



Starting the Conversation

Town Hall Meetings on Fetal Alcohol Spectrum Disorders

April 2004



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence

Starting the Conversation Town Hall Meetings on Fetal Alcohol Spectrum Disorders

April 2004

Draft

U.S. Department of Health and Human Services
Substance Abuse and Mental Health Services Administration
Center for Substance Abuse Prevention

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All birds have wings. But not all birds can fly.
— *Parent of a child with fetal alcohol syndrome*

EXECUTIVE SUMMARY

In 2002 and 2003, the Substance Abuse and Mental Health Services Administration (SAMHSA) convened 15 Town Hall meetings on fetal alcohol spectrum disorders (FASD). This report summarizes the testimony at the meetings. It also offers suggestions for future actions based on the findings.

Fetal Alcohol Spectrum Disorders

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. It refers to conditions such as:

- Fetal alcohol syndrome (FAS)
- Fetal alcohol effects (FAE)
- Alcohol-related birth defects (ARBD)
- Alcohol-related neurodevelopmental disorder (ARND)

Children with FASD experience lifelong difficulties. Problems that emerge over time may include:

- Decreased intellectual functioning
- Deficits in verbal learning, spatial memory, and reasoning
- Cognitive motor deficits
- Slowed reaction time
- Balance problems

In addition, children with FASD have impaired social skills. They may engage in inappropriate behaviors, such as public outbursts and unwanted touching.

The FASD Center for Excellence

In 2001, SAMHSA was charged with oversight of the FAS Center for Excellence. To reflect recent changes in terminology, the Center is now referred to as the “FASD Center.”

The FASD Center was established in Section 519D of the Children’s Health Act of 2000 (42 USC 290bb-25d). The Act specified the following mandates:

- Study adaptations of innovative clinical interventions and service delivery improvement strategies for children and adults with FASD and their families.
- Identify communities with exemplary comprehensive systems of care for such individuals so that they can provide technical assistance to other communities attempting to set up such systems of care.

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- Provide technical assistance to communities that do not have a comprehensive system of care for such individuals and their families.
- Provide training to community leaders, mental health and substance abuse professionals, families, law enforcement personnel, judges, health professionals, persons working in financial assistance programs, social service personnel, child welfare professionals, and other service providers on the implications of FASD and early identification of and referral for such conditions.
- Develop innovative techniques for preventing alcohol use by women in childbearing years.
- Perform other functions, to the extent authorized by the Secretary after consideration of recommendations made by the National Task Force on Fetal Alcohol Syndrome.

In its first year, the FASD Center sought input from various FASD constituency groups to operationalize these mandates. It did so in two main ways:

1. A steering committee composed of researchers, Federal agency representatives, and family advocacy groups
2. Town Hall meetings

Town Hall Meetings

The Town Hall meetings allowed various FASD constituency groups to identify areas of need and share information on available services to prevent and treat FASD. Participants included:

- Persons with FASD
- Families and caregivers of persons with FASD
- Service providers
- Researchers
- Policymakers
- Community leaders

Testimony addressed both needs and best practices. Most people focused on gaps in prevention and treatment services. Participants identified two primary needs:

1. Respite care
2. Greater understanding of FASD by various systems of care, including:
 - Education
 - Mental health
 - Substance abuse treatment
 - Criminal justice and legal systems
 - Vocational programs
 - Health care
 - Income programs (e.g., medical assistance, Social Security)

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Participants shared many specific needs, including the following, which were mentioned across several meetings (numbers in parentheses equal the number of times the issue was mentioned):

- Appropriate services for individuals with FASD and their families in every system of care (~100)
- Diagnostic services (~75)
- Adequate training of all providers working with individuals with FASD (~60)
- Job support for persons with FASD and help managing money (~50)
- Effective prevention strategies (~35)
- Community education about FASD, such as warning signs where alcohol is sold (~30)
- Alcohol treatment for women (~20)
- Recognition of FASD as a disability (~20)
- Physicians' understanding of FASD and their role in prevention (~15)
- Supported housing options for adults with FASD (~15)
- Psychiatric expertise on psychopharmacology for FASD (~10)
- Financial assistance (~10)
- Enactment and enforcement of adoption disclosure laws on adoptees' prenatal alcohol exposure (~10)

The FASD Center has developed the following policy recommendations based on issues raised in the testimony:

- Encourage or require States to recognize FASD as a disability regardless of IQ.
- Require mandatory training on FASD for all staff working with persons with special needs.
- Require warning signs on the dangers of alcohol use during pregnancy to be posted at point-of-sale establishments.
- Encourage States to help women of childbearing years who have alcohol and drug problems receive nonabortifacient family planning services.
- Encourage States to adopt or enforce disclosure laws in the foster care and adoption system.
- Ensure that psychiatric medications that might be used with children and adolescents with FASD are tested in children and adolescents with FASD.

The FASD Center is working to address the needs identified at the Town Hall meetings. In addition, some of the Town Hall meetings addressed specific populations. For example, outreach for the Minnesota and Arizona Town Hall meetings targeted Native Americans. A Town Hall meeting held in Baltimore in conjunction with a summit for women in recovery included women from various local treatment centers.

Town Hall meetings were held in:

- Washington
- Colorado
- Texas
- Florida
- Illinois
- Michigan
- Alaska

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- Mississippi
- California
- South Dakota
- New York
- Washington, DC
- Maryland
- Minnesota
- Arizona

Convening the meetings helped raise awareness about FASD and increase support for State efforts. Governor Pataki of New York issued a proclamation advertising the Town Hall meeting. Senator Daschle of South Dakota and his wife prepared a taped greeting for the South Dakota Town Hall meeting. In addition, Florida and Mississippi followed up on the Town Hall meetings with FASD projects, such as an FAS interagency group. Maryland activists used the Baltimore Town Hall meeting and accompanying women's summit to launch State FASD efforts. The meetings also helped facilitate State efforts by bringing together multiple agency representatives from various service systems.

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INTRODUCTION

In 2002 and 2003, the Substance Abuse and Mental Health Services Administration (SAMHSA) convened 15 Town Hall meetings on fetal alcohol spectrum disorders (FASD). This report summarizes the key testimony at the meetings. It also offers suggestions for future actions based on the findings.

FETAL ALCOHOL SPECTRUM DISORDERS

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. It refers to conditions such as:

- Fetal alcohol syndrome (FAS). Children with FAS have characteristic facial features, such as a smooth philtrum and small eye openings. They also have growth deficiencies and neurologic damage. Problems that emerge over time may include:
 - Decreased intellectual functioning
 - Deficits in verbal learning, spatial memory, and reasoning
 - Slowed reaction time
 - Balance problems
 - Cognitive motor deficits (NIAAA, 2000)
- Fetal alcohol effects (FAE) has been used to refer to symptoms of FAS without the characteristic facial features.
- Alcohol-related birth defects (ARBD) includes malformations in the skeletal and major organ systems.
- Alcohol-related neurodevelopmental disorder (ARND) refers to central nervous system deficits in the absence of the physical features of FAS.



Child With FAS

Researchers in the United States first identified FAS in 1973 (Jones & Smith, 1973). Since then, estimates of FAS prevalence have varied. Currently, the incidence rate for FAS is estimated between 0.5 and 3 per 1,000 live births in the United States.

Approximately 2,000 to 12,000 children are born each year with FAS (Streissguth, 2001). FAS occurs more often than spina bifida, Down syndrome, and muscular dystrophy combined. FASD, including FAE, ARBD, and ARND, occurs even more often.

Despite the many physical impairments of persons with FASD, their behaviors often pose the greatest problems for themselves, their caregivers, and society. Many are not recognized as mentally disabled and are held to standards they cannot meet. It is important to recognize individuals with FASD, because their behavior clearly differs from other persons. They also may differ from those with other types of mental disabilities or psychiatric conditions.

As this report will show, everyone has a role to play in recognizing and addressing the problem, including:

- Educators

- Parents and other caregivers
- Social service and youth agencies
- Criminal justice agencies
- Physicians and other health care providers

Common Behaviors and Characteristics of Persons With FASD

- Superficial bonding to family
- Lying and manipulation of family members
- Little impulse control
- Difficulty associating behavior with consequences
- Focus on immediate gratification
- Hyperactive in non-goal-directed activities
- Need for constant supervision
- Poor social skills with few, if any, long-term friends
- Rage, volatility, and violent outbursts
- Extreme vulnerability to peer pressure, a moral chameleon
- Unable to understand the need for rules and social cooperation
- Childlike innocence despite repeated offenses and consistent consequences

Source: FAS Family Resource Institute.

THE SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Part of SAMHSA's mission is to decrease substance abuse by bringing effective prevention strategies to communities. SAMHSA has two primary strategies to reach this goal:

1. Identifying, supporting, and promoting effective substance abuse prevention practices
2. Building the capacity of States, communities, and other groups to apply such practices effectively

THE FASD CENTER FOR EXCELLENCE

In 2001, SAMHSA was charged with oversight of the FAS Center for Excellence. To reflect recent changes in terminology, the Center is now referred to as the FASD Center. The FASD Center was established in Section 519D of the Children's Health Act of 2000 (42 USC 290bb-25d).

The Children's Health Act specified several mandates for the Center:

- Study adaptations of innovative clinical interventions and service delivery improvement strategies for children and adults with FASD and their families.
- Identify communities with exemplary comprehensive systems of care for such individuals so that they can provide technical assistance to other communities attempting to set up such systems of care.

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- Provide technical assistance to communities that do not have a comprehensive system of care for such individuals and their families.
- Provide training to community leaders, mental health and substance abuse professionals, families, law enforcement personnel, judges, health professionals, persons working in financial assistance programs, social service personnel, child welfare professionals, and other service providers on the implications of FASD and early identification of and referral for such conditions.
- Develop innovative techniques for preventing alcohol use by women in childbearing years.
- Perform other functions, to the extent authorized by the Secretary after consideration of recommendations made by the National Task Force on Fetal Alcohol Syndrome.

In its first year of operation, the FASD Center sought input from FASD constituency groups to operationalize these mandates. It did so in two main ways:

1. A steering committee composed of researchers, Federal agency representatives, and family advocacy groups
2. Regional Town Hall meetings

TOWN HALL MEETING SITES

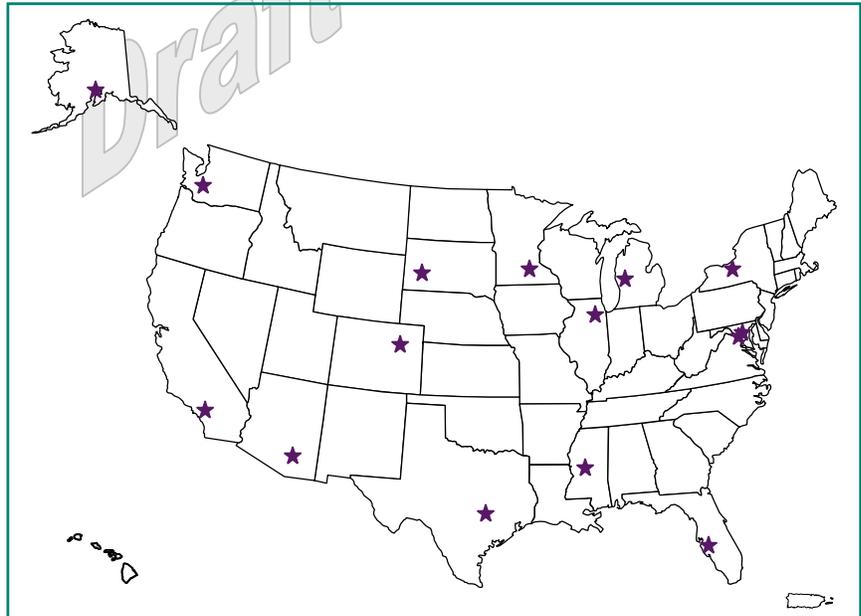
Working with the FAS Family Resource Institute (FAS FRI) and the National Organization on Fetal Alcohol Syndrome (NOFAS), the FASD center convened Town Hall meetings in 14 States and the District of Columbia. The map shows the Town Hall locations.

2002

March 28: Olympia, WA
June 7: Denver, CO
June 21: Austin, TX
July 24: Clearwater, FL
August 2: Chicago, IL
August 17: Newaygo, MI
November 20: Anchorage, AK

2003

February 12: Jackson, MS
March 26: Los Angeles, CA
April 24: Rapid City, SD
May 21: Buffalo, NY
June 18: Washington, DC
September 8: Baltimore, MD
September 18: Bloomington, MN
October 18, 2003: Tucson, AZ



TOWN HALL RECRUITMENT AND PLANNING

The FASD Center contracted with FAS FRI to organize most of the Town Hall meetings. FAS FRI is a family advocacy and support group in Washington State. FAS FRI recruited participants for the Town Hall meetings by sending brochures to professionals and related organizations by e-mail and regular mail.

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In addition, members of FAS FRI traveled to various sites to promote the Town Hall meetings. In each host city, FAS FRI contacted local newspaper, radio, and television stations and sent information packets about the FASD Town Hall meetings to request advertising.

FAS FRI solicited contacts from FASD-related professional organizations. These included organizations devoted to education, health, corrections, substance abuse, and adoption. FAS FRI also used available family mailing lists in each designated region. FAS FRI sent 10,000 brochures to each site to advertise the Town Hall meetings (see Appendix A for a sample brochure).

NOFAS organized the Washington, DC, and Baltimore Town Hall meetings. The Alaska Office of FAS organized the Alaska meeting. Both organizations used recruiting methods similar to FAS FRI. In addition, NOFAS planned the Washington, DC, Town Hall meeting in conjunction with NOFAS's annual awards reception. The Baltimore Town Hall meeting was planned in conjunction with the "Hope for Women in Recovery" summit.

The organizers chose locations that would support maximum participation. Additional recruitment measures were added according to State-specific needs:

- Colorado has an active and well-established FAS Substance Abuse Coalition, a Centers for Disease Control and Prevention (CDC) Surveillance Project, and an official FAS State Coordinator. Therefore, recruitment revolved around existing networking groups.
- Texas did not have any established networks. Therefore, the first step was to invite officials from various State agencies.
- The Florida site for the Town Hall meeting was chosen specifically for collaborative purposes because stakeholders were already gathered to attend the national Healthy Mothers/Healthy Babies conference.
- The Chicago site was chosen because it was the host city for the 2002 conference of the National Council on Adoptable Children (NACAC).
- The Alaska Town Hall meeting was held prior to the Alaska FAS Summit to take advantage of high attendance there.
- Rapid City was chosen because South Dakota is a member of the Four-State Consortium on FAS.
- Bloomington, Minnesota, and Tucson, Arizona, were chosen because of extensive activity related to FASD and to encourage Native American participation. Town Hall meetings were open to the general public. In Bloomington, a separate session was held for Native Americans.

The Town Halls attracted more than 800 participants (Table 1). Attendees came from various States, including Washington, Oregon, Colorado, Texas, Mississippi, Florida, Illinois, Wisconsin, Michigan, Alaska, California, South Dakota, New Mexico, New York, Virginia, Maryland, Pennsylvania, Minnesota, and Arizona, as well as Washington, DC. Persons testifying at the Town Hall meetings included:

- More than 200 parents and caregivers, including 160 adoptive parents, 19 foster parents, 14 grandparents, 6 stepparents, 12 mothers in recovery, and 5 birth mothers
- Thirty individuals with FASD



Video Clip of Mother Sharing Child's Paper on FAS

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- About 140 professionals
- About 20 community leaders

At each site, the organizers convened a VIP panel of individuals involved with FASD prevention and treatment to hear testimony (see Appendix B for a list of panel members). The members varied with each site but usually included State and local government officials. In addition, professional representatives of various law enforcement, criminal justice, and mental health systems participated. Several universities were also represented on the VIP panels, including University of Washington, University of Alaska, Chicago Medical School, Black Hills State University, University of South Dakota, University of Maryland, and San Diego State University.

Table 1. Town Hall Meeting Attendance

Location	Attended	Testified*	VIP Panel
Washington	100	52	10
Colorado	42	23	9
Texas	60	35	10
Florida	29	22	14
Illinois	54	30	12
Michigan	81	59	13
Alaska	24	56 [†]	12
Mississippi	34	19	17
California	46	33	9
South Dakota	77	36	18
New York	33	22	20
Washington, DC	83	45 [‡]	13
Maryland	67	24	11
Minnesota	49	34	18
Arizona	38	42	11
Total	817	532	197

* Includes written testimony.

[†] Includes testimony by phone, in writing, and by online form.

[‡] Additional 220 pieces of written testimony submitted electronically.

Federal agencies represented included:

- SAMHSA
- CDC
- National Institute on Alcohol Abuse and Alcoholism
- Health Resources and Services Administration
- Department of Education
- Department of Justice
- Social Security Administration
- Indian Health Service

National organizations represented included the Arc, March of Dimes, National Organization on Fetal Alcohol Syndrome, National Association of State Alcohol and Drug Abuse Directors, and National Council on Disability.

Before each Town Hall meeting, FAS FRI and NOFAS held advocacy workshops to help participants develop testimony. Those not wanting to testify onsite were asked to submit their testimony in writing. Nearly 350 people provided written testimony. Some written testimony was read into the record.

MEETING PROCEDURES AND DATA ANALYSIS

Town Hall meeting participants were asked to summarize their testimony in a brief outline. Generally, participants were given 5 minutes for oral testimony. In Baltimore, participants had the option of testifying in private.

The testimony of all those participating was recorded on audiotape. A technician videotaped individuals who provided written permission. Meeting notes and videotapes were reviewed. Reviewers noted:

- General tone of the meeting
- Problems and needs discussed
- Suggestions and recommendations made by those testifying

Reviewers examined both the written and video transcripts and developed codes for topical categories. Then they developed summaries for each category. Coding relied on key themes presented to the participants in the advocacy workshop:

- Services needed
- Services available
- Obstacles

Based on data analysis, reviewers created subcategories:

- Clinical services
- Relief services
- Community education
- School system reform
- Legal and judicial reform
- Provider education
- Prenatal care and prevention
- Financial services
- Barriers to service and treatment

Reviewers entered a summary of each piece of testimony into a database. To determine how many times an issue was mentioned, reviewers searched the testimony text for keywords (e.g., “respite”). Reviewers also used the database to generate the number of persons testifying from particular groups (e.g., parents, professionals).

RESULTS

In several States, the Town Hall meetings had an immediate effect. The meetings helped raise awareness about FASD and increase support for State efforts. Governor Pataki of New York issued a proclamation advertising the Town Hall meeting (see Appendix C). Senator Daschle of South Dakota and his wife prepared a taped greeting for the Town Hall meeting.

The Town Hall meetings also helped facilitate State efforts by bringing together multiple agency representatives from various service systems. This was the first time these service systems jointly looked at the issue of FASD. Florida and Mississippi followed up on the Town Hall meetings with FASD conferences and projects.

Participants at the Town Hall meetings provided great insight into the lives of people living and working with FASD. Their testimony is summarized according to the related legislative mandates of the FASD Center. This organization will help the FASD Center respond to needs while addressing statutory requirements.

See Appendix D for key points raised in testimony at each Town Hall meeting. Appendix E describes recommended types of FASD training. Additional information and resources about FASD are available at fascenter.samhsa.gov.

Mandate 1: Clinical Interventions and Service Delivery

Town Hall participants spoke of service gaps in multiple systems of care. They were especially frustrated by the lack of respite care and difficulty getting services from schools. At almost every Town Hall, respite was mentioned (26 mentions), as well as problems with schools (about 50 mentions).

Clinical Services

Parents noted many needs, including:

- More precision in diagnosis and referral services
- Greater attention to special education intervention strategies
- More education for those working in the mental health field
- More services for pregnant women struggling with addiction
- Respite care for parents

Centralization of services was deemed paramount. As one participant explained, “Without information and public awareness, coordination won’t work.” Several professional service providers called for greater cooperation and coordination of services for children with FASD and their families.

One service provider noted that in her treatment of pregnant women with addiction problems, she observed that most avoid prenatal agencies. They fear being blamed and becoming victims of another agency’s actions, such as having their children taken away. It is critical that the women feel safe and protected in order for treatment to work.

Many pregnant women with addiction problems fear having their children taken away.

Some parents linked clinical service interventions with failed attempts to medicate their children. Many question physicians' readily dispensing psychotropic medicines to children with FASD. Parents expressed concern about the number and strength of medications, as well as possible addiction. One mother reported that her son had become addicted to his medicine. She argued for nutritional alternatives.

Parents also mentioned co-occurring disorders in children with FASD, such as bipolar disorder. Since FASD is not a psychiatric diagnosis, it is often not recognized by mental health professionals. In addition, the symptoms of FASD resemble many mental health diagnoses.

As many parents explained, when they sought mental health services for their children, the possibility of prenatal alcohol exposure was not considered. Similarly, if a co-occurring disorder was recognized, many mental health care providers preferred to use a diagnosis other than an FASD in order to get insurance coverage.

Participants also expressed a need for change in the IQ qualification level for developmental disability services. Many parents reported that their children with FASD had IQs too high to qualify for such services. Many States have set IQ limits for disability eligibility, with several States using a score of 70 as the cutoff point.

During one Town Hall meeting, a panel member commented on Ann Streissguth's secondary disabilities study (Streissguth, Barr, Kogan, et al., 1996). This study found that individuals with FAS had a mean IQ of 79. Scores ranged between 29 and 120. Individuals with fetal alcohol effects (e.g., ARND) had a mean IQ of 90, with a range between 42 and 142. Parents asked for a broader Federal classification of developmental disabilities so that persons with FASD could qualify for benefits and services.

Better health care management was a primary concern. Parents expressed their frustration with health care providers who did not know how to refer or provide appropriate services for family members with FASD.

Parents were particularly concerned about pediatricians, social workers, psychologists, and psychiatrists. They want these professionals to have training and resources to assist families in obtaining health care, because they are often the first point of contact for parents seeking services. When these clinical services are not available, children and youth with FASD often suffer serious consequences.

Relief Services

Several parents testified about the need for relief services, often referred to as respite care. One parent testified that whole families are affected by FASD and should have some sort of support resource. This parent described her own sense of "deep grief" and how other siblings are often neglected because of the high demand for attention from children with FASD. She asked for some form of service that would relieve her from the worry and stress of everyday life.

Parents also expressed concern about their children's need for safe and constant supervision. As many parents asked, "Where can parents turn safely for help?" since an "FASD child is not safe outside the home." This need continues through adulthood, and many expressed the need for group homes or other supervised living arrangements. One parent commented that "we provide supervised living arrangements for those who have sustained brain damage in accidents, but we cannot extend that understanding to someone who has sustained brain damage prior to birth."

A child with an FASD is not safe outside the home.

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Most parents described having no external source of help for respite care. Because FASD is poorly recognized and diagnosed, respite care is neither funded nor supported by the medical or mental health community at large.

One parent described the help she received from community volunteers. “Some people would volunteer to help me; they would care for him once, never to be seen again.” Parents acknowledged the enormous strain and responsibility placed on respite care workers. They asked for more professionally trained respite care workers to help deal with the basic challenges an affected family faces.

One parent mentioned specifically the difficulty of finding respite care for her profoundly affected daughter with FAS. She described her quandary when she was told that her child had too many problems to qualify for respite care services. Because of the behavior problems that often accompany FASD, respite care and ordinary day care services can be impossible to find. As one parent stated, “Try to find a day care for a kid over 12 who has a sexual outburst background....It was just the absolute shock and disappointment of a lifetime that there wasn’t any care.”

Many testifying mentioned hospitalization or incarceration of their children as the only measure of respite care that they have received. One parent noted that a State service agency said that the only way they could receive any form of care would be to “set the child up” to commit a crime. Then he could be jailed in a juvenile detention center.

Other parents described using the family savings to pay for a child’s care. As one mother described, “We had to take out a home equity loan of about 20,000 to 30,000 dollars in order to pay for our child’s care.”

One couple had to take out a home equity loan to pay for their child’s care.

Many parents described the demise of a marriage or family structure because of the immense amount of time and energy that the care of a person with an FASD requires. As one parent noted, “My wife and I have not had a date in years. No one will watch our daughter.” Another commented, “The mental, physical, financial, and emotional toll on our family from the adopted FAS kids almost destroyed our family.” Parents of youths or teenagers with FASD often report not feeling safe or stable in the home because of a youth’s chaotic behavior.

This problem was evident in the testimony of several adolescent siblings of a person with an FASD, who became very emotional. In many cases, they were unable to read their written testimony. One parent noted, “Our home is not safe because our son invites strangers in.” Lack of discretion along with minimal cause-and-effect reasoning among persons with FASD led many parents to give the category of respite care top priority as a needed intervention service.

School System Reform

At every Town Hall meeting, participants testified about the lack of sufficient special education resources for those with FASD. They expressed deep frustration with the system. As one parent said, “I don’t think my job should be an advocate....My job is to be the Mommy.” Their difficulties led many parents to home-school their children with FASD.

Many parents sought individual education plans (IEPs) for their children. However, many schoolteachers and administrators did not follow the plans. In some cases, school psychologists were not helpful either. Parents found this situation unacceptable. As one parent noted, “Teachers are busy, but they need to be informed.”

Most parents linked the failure of the school system to a lack of awareness of FASD as a legitimate disability. School systems thus lacked interest in arranging special education or vocational services. Some parents also mentioned the lack of uniformity of services between States. One mother commented, “Our move to the Florida school district was a nightmare.”

One problem common to those who testified is difficulty maintaining eligibility for services. Many parents testified that their children were denied services because their IQs were too high. Similarly, many parents spoke of receiving services for their children and being told later that the child did not need them anymore because of successful adaptation or test scores. Several parents spoke about their children losing access to special education services upon successful completion of grade school. Parents insisted that FASD be understood as disorders in which mental deficits and learning difficulties ebb and flow throughout the child’s life.

Many parents reported being forced from an advocate position to an adversarial position in their struggle with the school system. Similarly, students with FASD reported feeling misunderstood and neglected by teachers. One young student testified that he would like to see a school system specifically trained to understand the full range of his needs. When asked which aspect of the school system causes him greatest difficulty, he remarked, “the teachers.”

Some parents who could not get their children appropriate services in the public schools in their State turned to private schools. Despite smaller classroom sizes and student-teacher ratios, however, private schools were in no way equipped to deal with FASD. Several parents turned to home-schooling.

Often, the success of an individual child’s education plan depends on the quality and effort of a particular teacher. Those who found solace in private schools still expressed the need for increased funding and awareness for public schools. As one parent noted, “Public schools were detrimental for my son.”



**Video Clip of Parent
Testifying on Her Role**

Students with FASD often
feel misunderstood and
neglected by teachers.

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Most parents expressed concern about the lack of sensitivity to the needs of children and young adults with FASD. One participant reported, “The greatest obstacle for [my] daughter was the lack of a sensitivity process for students with problems, which leads to ridicule by peers.”

Parents also complained that school systems worsened behavior problems by separating children with FASD from their peers. Parents noted that their children with FASD were often placed with children who have behavior problems, instead of in special education classrooms. These placements can expose children with FASD to inappropriate peer influences that can harm their education.



Video Clip of Parent Testifying About Classmates' Teasing

One professional noted that secondary outcomes associated with FASD continue to occur because, as a society, “[W]e do not make it o.k. to have FAS, or any disability for that matter. It is not o.k. in our schools and community to learn differently, to require extra time to reach personal goals or system goals, to falter, to be helped up, and to need help throughout one’s life.” Similarly, a parent commented, “I’d like to see systems dispense with standard education and testing. Because you know what? One size doesn’t fit all.”

Other testimony included one parent who linked the failure of the school system to her son’s present incarceration. She was told, “There is no place for your son in this system.” This parent also acknowledged the lack of vocational training in the school system. Many parents called for more funding for schools that would lead to more training for special education teachers and more resources and tools for the classroom. Some suggested mentoring services.

Many parents relayed how sharing information about FASD was met with hostility on the part of teachers and health care providers. As one mother noted, “I want an education that is good, so every principal, child care worker, or psychiatrist recognizes FAS. I would like the public to know what it is and how it manifests itself.”

Mandates 2 and 3: Comprehensive Systems of Care and Technical Assistance to Communities

Lack of services is a major issue. More than 100 people testified about difficulty obtaining services. Several noted the need for consolidation of services. About 50 individuals mentioned the need for greater awareness of FASD. Many people also cited the need for legal and judicial reform, as many individuals with FASD become involved with the justice system. Finally, more than 60 people raised the issue of diagnosis.

Awareness

Numerous people called for more education of the larger community. People need to know about FASD and understand the nature and use of alcohol in American society. Most parents addressed some aspect of community insensitivity to FASD. Some mentioned lack of funding or services. Others talked of the general misunderstanding about the “invisible disability.”

Several participants noted the need for more community awareness of alcohol as a drug. Specifically, parents offered their support for measures that would help Americans understand their culture,

particularly why and how alcohol is consumed. Many linked this suggestion to prevention of alcohol abuse for women of childbearing age.

Participants also asked that greater attention be given to the advertising industry. They expressed concern about the glorification of alcohol in television ads and billboards. One participant in Texas gave State-specific examples of commercials and advertising ploys that misrepresent the use of alcoholic beverages.

Some participants noted a problem with warning labels on alcohol containers. Consumers do not see these labels when alcohol is served in a glass or pitcher. Therefore, participants suggested placing warning signs at point-of-sale establishments to raise awareness about the dangers of alcohol use during pregnancy. A related suggestion was to place warning labels on all alcohol containers so that the label is clearly visible and readable.

One mother said that her Ph.D. and M.P.H. degrees increased her interest in FASD. Health care providers, educators, and the public were of little help. She said, “We need to stop the fragmentation of multiple systems” and “teach parents and community members how to contribute to a healthy parenting experience.”

We need to stop the fragmentation of multiple systems.

Community Support

Other parents found a great deal of support from family-oriented networks with a common concern about FASD. Organizations such as the Family Empowerment Network (FEN) and FAS FRI were reported as very successful information sources that provide a venue for greater collaboration among parents about communitywide information.

Parents use these resources to share ideas about parenting strategies, professional resources, and contact information for referrals. Many parents also described these types of connections as “a bit of respite in itself.”

Increased community education was also tied to greater availability of support for families parenting children or young adults with FASD. One common suggestion was to create a network of lifetime advocates for people with FASD. A lifetime advocate would assist a person with an FASD through major life transitions and responsibilities. The advocate would also assist in times of crisis or when specific barriers to treatment or services arose.

As one person testified, in Washington State, lifetime advocates have been used for women and children with FASD with great success. Many young adults with FASD supported this suggestion. Their testimony centered on the desire to live independently, “but with help.”

Another suggestion for community education and more effective intervention strategies centered on the need for vocational training for persons with FASD. One parent suggested continuing education courses at community colleges that could help those with FASD better adapt to independent living. Topics could include budgeting, time management, and job skills. Other parents asked that such vocational training be made available in the public school system so that young adults with FASD could seek work after graduating.

Most of the suggestions for increased community education hinged on the assumption of increased funding for FASD as a recognized disability. Many of the parent-advocates described their organized efforts at education as “grassroots.” As one director of a prevention network noted, “We work mostly in church basements and around dining room tables.... There are many who can and will help with prevention” if the proper resources are allocated.

Legal and Judicial Reform

Funding was reported as crucial in implementing strategies and services to effect legal and judicial reform. Other concerns ranged from policies aimed at “protecting those within the womb” to disclosure laws for adoption and foster parenting. For example, many participants testified about poor foster care systems. One participant criticized child protective services as having an institutional attitude that sets children up to fail in a bad adoption system.

Several parents also testified about the need for nationwide uniformity of adoption disclosure laws. One participant reported having no knowledge of her child’s background before adoption. Another participant stated that “social services denies that kids have problems related to FASD and hide information” from adoptive and foster parents. Disclosure of medical information that would assist in the recognition and treatment of FASD is critical.

Another participant proposed posting alcohol warnings in various establishments selling alcohol. This participant suggested the government was too lax in regulating alcohol-related advertising. He wants to see more awareness about FASD because, as he emphasized, “Awareness will help policy and practice.”

Other legislative areas of concern were:

- Control over advertising
- Funding and support for diagnosis and treatment
- Provision of legal advocates to represent the interests of children with FASD

One person testified, “Advertising should be controlled when it is adversely impacting the public.”

Unfortunately, many children with FASD become wards of the criminal justice system. One physician noted that in Canada, 50 percent of incarcerated youth may have some degree of alcohol-related cognitive deficits. Another testified about the rampant misdiagnosis in the prison system, as well as the many obstacles to providing treatment. He noted that many of the patients he treats have been diagnosed with bipolar disorder, although an FASD would be more appropriate.

Many children with FASD become wards of the criminal justice system.

This physician also noted that judges often do not release incarcerated, at-risk pregnant women for treatment until the child is born. Therefore, the woman’s alcohol problem is not addressed, which could put her child at risk. He also noted the bureaucratic obstacles to providing substance abuse treatment. Variations in rules and regulations of individual prison systems can create problems.

Providing appropriate medical care to individuals with FASD in prison can be difficult. It is especially hard to provide ongoing mental health care effectively. Because of the high number of persons with FASD in the criminal justice system, many parents and professionals asked for an increase in counseling services. Many professionals also advocated for disability screening.

Many parents complained that the criminal justice system is used to “hold” persons with FASD in times of crisis. Several parents reported having a close relationship with local authorities. Often, these parents were forced to call the police to temper severe emotional outbursts from their children.

Unfortunately, early and repeated interventions by State or local police can lead to a pattern of subsequent offenses as persons with FASD enter their young adult years. One parent noted, “They are often arrested as accomplices or they admit to crimes only to please the police.” A probate judge supported the notion by stating, “Prisons are 25 to 50 percent full of FASD people; it affects their brain and no amount of punishment will change their behavior.”

Diagnosis

There was widespread concern about the difficulty in receiving an appropriate diagnosis. Some participants reported being overwhelmed by “too many diagnoses and treatments.” Others complained, “You have to be lucky to get an accurate diagnosis with FAS.”

Many parents expressed extreme frustration with the lack of consistent diagnostic criteria for FASD. Because of this deficit, few professionals recognize FASD as a disability. In addition, misdiagnosis is an issue.

Many parents reported that their children received incorrect diagnoses because providers did not know the prevalence and characteristic symptoms of FASD. Therefore, children were often inappropriately diagnosed with one or more neurologic or mental health disorders, including:

- Attention deficit-hyperactive disorder (ADHD)
- Autism
- Oppositional defiant disorder (ODD)
- Sensory integration disorder
- Anxiety disorder
- Bipolar disorder
- Attachment disorder
- Posttraumatic stress disorder (PTSD)

Without proper diagnosis, many children were erroneously medicated.

Participants also noted the need for a cost-effective screening tool. Because an FAS diagnosis is difficult for parents to obtain, many advocated for a screening tool that might lead to an earlier diagnosis. Some tool to screen infants prenatally exposed to alcohol is crucial to any prevention or intervention effort.

Mandate 4: Training

General Public

Training is needed to help everyone understand FASD. One participant told of her experience educating youth about the dangers of alcohol and pregnancy and how preventive education is best started very early, around the age of 10. However, most who spoke about FASD education noted the need to “educate the educators” and to be informed as parents so as to better advocate for children with FASD. One parent indicated that it is difficult to find effective strategies. He said, “There seems to be no rhyme or reason to what works or what doesn’t work.”

Many parents of children with FASD reported that they found some useful information and support using the Internet. However, many noted that they had to seek the answers to their complex medical problems. They found this to be another frustration in caring for their children.

Provider Education

A resounding call for provider education was heard at all the Town Hall meetings. Perhaps the most prevalent suggestion was education for professionals. Ideally, an “ongoing, systematic, and organized training program” would be developed to increase knowledge and understanding of FASD. Several participants called for more provider education to combat the ignorance that too often leads to judgmental attitudes in treatment and recovery services.

Calling for greater funding for provider education, a neonatologist testified that to move the “birth defects agenda forward, we must be responsible in providing an accurate diagnosis and referral for service.” One parent added that the “lack of training equals a lack of services.”

A mother currently in recovery also called for provider education. She explained that none of the treatment programs she was in while pregnant gave in-depth information about FASD and the consequences for the child and family. They provided information about the causes of addiction and the steps toward recovery. However, they did not discuss the effects of alcohol on the fetus or the difficulties of raising children with FASD.

Participants called for widespread training for all types of service and health care professionals. Parents requested uniform dissemination of information about FASD so that intervention strategies would be effective and streamlined. Professionals cannot responsibly refer patients to service-oriented resources if they remain ignorant about FASD.

Parents were particularly concerned about mental health providers. Parents want a system in which psychologists learn about FASD and are required to know how to deal with the issues that accompany a diagnosis. The current lack of FASD training among psychologists has created an atmosphere where, as one participant noted, “ARND diagnosis is rare or more often diagnosed as multiple individual problems.”

Parents recommended increased training for prison officials, psychiatrists, social workers, and anyone involved in the criminal justice process. Of prime concern is sentencing for crimes committed by persons with FASD. Several representatives of State criminal justice systems admitted that awareness of FASD as a disability is virtually nonexistent in the court and prison systems.

Mandate 5: Preventing Alcohol Use in the Childbearing Years

Many parents highlighted strategies more closely related to intervention. However, their testimony implied the need for effective prevention strategies.

A starting point for FASD prevention is greater awareness of attitudes about alcohol. Many participants spoke of the need for more information dissemination, such as pamphlets, posters, and videos. As one health care provider noted, “We need more information, whatever it takes to get the message across.”



Video Clip of Birth Mother Testifying on Lack of FAS Information

A related issue is the widespread ambiguity in advice given to pregnant women about alcohol use. One physician testified that he is often asked, “How much alcohol can I drink while pregnant?” But no one ever asks, “How much heroin, cocaine, strychnine, etc.?”

Women often ask, “How much alcohol can I drink while pregnant?” But no one ever asks, “How much heroin or cocaine can I use?”

Several people also noted the misleading information physicians give to many pregnant women. One nurse commented that women say, “Well, it’s o.k. My doctor said I could have a little drink. It will help me relax.” Most OB-GYN textbooks do not recommend abstinence, if they even mention alcohol and pregnancy. Thus, women fail to understand the effects of alcohol on fetal brain development.

Many participants suggested a comprehensive treatment center that could incorporate prevention and intervention strategies into a statewide interagency plan with “full wraparound care.” They suggested that any type of prevention measures begin with awareness of the cost of raising children with FASD. One participant noted that the cost of providing services to children with FASD is rising and that prevention is cost-effective.

Without proper prenatal care and effective and accessible prevention strategies, children will continue to have FASD. As one father noted, they will be “doomed to mediocrity” and a turbulent life. One grandmother suggested informing young women about contraception so that they do not get pregnant when they are drinking.

Similarly, participants expressed concern about women not being tested for substance use during pregnancy. This causes treatment centers to lose many women who would otherwise be referred for treatment. One of the main concerns was that women do not understand the risk involved in substance use during pregnancy.

Because of the common misunderstanding about alcohol use and pregnancy, one person related this issue to prevention and community education. This person suggested educating teens on alcohol use during pregnancy.

A major issue related to prenatal care and prevention is child care for women who seek treatment. Many health care providers mentioned the difficulties of treating pregnant women who already have children who may or may not have FASD. Many women do not complete treatment or cannot start because they lack child care for older children or fear losing their children after seeking treatment.

Overarching Issues

Some broad issues relate to all the legislative mandates. These include financial issues and barriers to services. The overriding message was that individuals and families need assistance in navigating systems and overcoming obstacles.

Financial Assistance

Most parents confirmed the overwhelming amount of money it takes to raise children with FASD. Aside from limited medical coverage, many parents noted the high cost of medications, as well as the lifelong medical costs that arise from auditory and visual difficulties, among other health problems.

Starting the Conversation

Lifetime costs associated with FASD have been estimated to range from \$1.4 million to \$5 million per person with an FASD, excluding the costs associated with incarceration (Streissguth, et al., 1991), mental health services, and lost productivity from unemployment.

Parents asked for increased funding for provider education as well as more funding for schools to implement quality special education services. Many parents noted that they were forced to give up a dual family income to provide home-schooling.

Participants also identified a need for financial assistance for general medical coverage, specifically dental and vision coverage; respite care; and legal costs. One parent described how her son has difficulty keeping a job. He is never at one job long enough to be eligible for benefits. Therefore, the family has had to cover his living expenses (food, clothing and housing, car payment, car insurance), as well as the cost of his medical bills and attorney's fees.

Due to inadequate health care coverage, it is difficult to obtain epidemiologic and surveillance data on FASD. This lack of data may be one reason that FASD does not receive the attention or resources it deserves. As one physician stated, "Uninsured parents prevent skilled evaluation of FASD; we must expand surveillance, develop and implement strategies to combat this."

Another concern was the cost of treatment for substance-abusing women. Many participants noted that even if treatment is mandated by the criminal justice system, insurance companies will not pay for it.

In addition, women entering treatment must show some type of financial responsibility, which many cannot do. Therefore, a health care provider suggested that the system allow payment alternatives, because demanding payment up front may prevent these women from entering treatment.

Barriers to Services and Treatment

An issue that became clear during all the parental testimony was facing specific barriers to treatment and services for children and young adults with FASD. Sadly, many parents said that educational agencies and health care providers were primary barriers to service. Most parents expressed their frustration with the bureaucratic pitfalls of finding and maintaining adequate treatment for their family members.

Specific barriers to service included:

- Underdiagnosis and misdiagnosis of FASD and any co-occurring disorders
- Lack of understanding by teachers, doctors, psychiatrists, social workers, nurses, principals, police, and judges that FASD is a disability
- Lack of medical insurance and appropriate coverage
- Lack of services and treatment facilities
- Restrictions on eligibility for services, such as age or IQ
- Difficulty obtaining birth records and medical history in adoption cases
- Lack of financial resources for medical, mental, and respite care
- Lack of special education resources
- Inadequate support for foster families or caregivers
- Little or no resources for child care when seeking substance abuse treatment

- Failure to recognize that FASD manifests in a variety of symptoms not always noticeable during a short visit or evaluation

Specific barriers to treatment change with any given population and escalate for special populations. Treatment for pregnant women with substance abuse problems can be difficult to find. One reason is that the substance abuse treatment system is often not accessible to special populations, such as women with young children, adolescents, and rural populations. In addition, ethnic and racial differences were noted in the Town Hall meetings as another impairment to adequate care, often due to language or cultural barriers.

Geography is another barrier to treatment. Many parents in rural areas reported an insufficient number of programs spread across their particular region. As one parent testified, “We need services that are not a hundred miles away.”

For children and youth with FASD, long travel times or lack of transportation make appropriate treatment and care difficult, if not impossible. In addition, the lack of cohesive interaction among treatment systems was reported as another barrier to efficient and effective care.

DISCUSSION

Participants at the Town Hall meetings raised three primary issues:

1. Public and professional awareness of FASD as a disability
2. Appropriate diagnostic criteria for persons with FASD
3. Difficulty obtaining appropriate educational and health care services

Obstacles most often mentioned were:

- School system insensitivity
- Lack of awareness and training among teachers and health care providers
- Lack of knowledge among physicians about the presenting symptoms of FASD in young children
- Inadequate referral services in health care
- Lack of benefits or support for birth and adoptive families with children diagnosed with FASD

In addition, the lack of understanding from the community at large contributes to isolation and despair among many parents raising children with FASD.

The primary themes were needed services, available services, and obstacles to primary care. Many participants touched on a variety of related issues, including:

- Clinical services
- Relief services
- Lack of diagnosis and related lack of services
- Inaccurate evaluation for services
- Denial of services and the related need for school system reform
- Community education

- Legal and judicial reform
- Provider education
- Financial assistance

State-specific issues included:

- Frustration with the school system (Texas and Florida)
- Concerns about alcohol advertising both nationwide and for local events (Texas, Washington)
- Lack of a centralized treatment and service center that could serve as a clearinghouse for information dissemination, education, and diagnostic and referral services (Michigan)
- Frustration with the lack of funding for effective support services (Illinois)
- Agency fragmentation harming the quality of services and intervention strategies (Illinois, Florida)
- Children being sent out of State for treatment (Alaska)
- Need for culturally appropriate treatment approaches (Alaska, South Dakota, New York, Arizona)
- Multigenerational alcohol problems related to poverty and unhealthy lifestyles (Mississippi, South Dakota, Minnesota)
- Lack of programs specific to FASD (Maryland)
- Need for funding of Native American programs (Minnesota, Arizona)

The general tone of the Town Hall meetings corresponded to the paramount problems noted in individual testimony. Many participants shared their difficulty in summarizing a lifetime of experience and relevant suggestions in 5 minutes. However, all participants embraced the opportunity and shared a vast array of information.

This exchange provided a sense of communal support and mutual understanding. It also instilled a sense of hope regarding future reform of existing services and implementation of new ones.

RECOMMENDATIONS

The recommendations can aid policymakers in implementing strategies in various communities. Although no single agency can carry out all the recommendations, these suggestions provide a starting point for creating a collaborative network to prevent and treat FASD. The recommendations are organized according to the legislative mandates for the FASD Center for Excellence.

Mandate 1: Clinical Interventions and Service Delivery

Clinical Services

- Establish legal guidelines regarding funding of FASD as a disability.
- Increase sensitivity from health care providers to the plight of pregnant women with addiction problems and change negative attitudes.
- Recognize FASD as a disability and properly allocate disability funds.
- Create more precise, robust terminology in describing and diagnosing FASD.
- Support and educate parents on the best strategies for teaching and caring for children with FASD.

Relief Services

- Establish organized and efficient ways for parents to obtain information and respite care services.
- Establish model group homes or supervised living situations for individuals 18 and older, connected with school-to-work transition programs, long-term mentoring services, and help for difficult problems such as inappropriate sexual behavior.

School System Reform

- Promote greater investment and commitment from the school system to each child's educational success, regardless of the particular disability.
- Implement vocational assistance and mentoring programs for adults with FASD.
- Implement teacher education on FASD as a learning disability, along with helpful classroom strategies.
- Increase funding for special education services.

Mandates 2 and 3: Comprehensive Systems of Care and Technical Assistance to Communities

Awareness

- Disseminate more information to families and young adults about the dangers of alcohol use during pregnancy.
- Increase awareness about the culture of drinking so that health care providers can counsel pregnant women not to drink.

Community Support

- Provide and train lifetime advocates for persons with FASD.

Legal and Judicial Reform

- Increase awareness in prison systems of FASD diagnoses.
- Educate judges and other court personnel likely to encounter persons with FASD in the courts.
- Provide equal access of incarcerated persons to medical care and prevention education.

Diagnosis

- Provide screening and diagnosis of FASD-related conditions for young children in high-risk situations, such as foster care, international adoptions, and homes with substance-abusing mothers.
- Develop consistent diagnostic criteria.

Mandate 4: Training

General Public

- Educate youth about the dangers of alcohol and pregnancy.

Provider Education

- Encourage health care providers to seek education about FASD and learn to make accurate referrals for services.
- Provide a systematic, ongoing training program for professionals about FASD.
- Increase funding for the study of brain development and FASD.

Mandate 5: Preventing Alcohol Use in the Childbearing Years

- Post alcohol warnings in establishments serving alcohol.
- Increase information about FASD in recovery programs and treatment facilities that support parenting and pregnant women:
- Increase funding for effective prevention strategies.
- Provide comprehensive outreach to pregnant women of childbearing age who are at risk for substance abuse.
- Provide contraceptive services for substance-abusing women.

Overarching Issues

- Allocate resources to parents and caregivers to enable them to be effective advocates for their children.
- Fund programs that can creatively meet the comprehensive needs of those with FASD.
- Regulate and reform the eligibility criteria for SSI benefits.
- Increase funding for organized systems of parent support groups.

Recommended Strategies for Caring for Persons With FASD

Parents testifying across the Nation had many parenting and educational suggestions for dealing with persons with FASD. They shared these suggestions because of the loneliness they felt as they struggled to create strategies to help their children with FASD and family to cope. Although these strategies can help, they have not been evaluated or endorsed by any government agency.

Many of the strategies are derived from a successful education plan for children with FASD. They focus on structure and reduction of overwhelming stimuli. They also include behavior management techniques. In addition, some parents focused on alternatives to medication, such as nutritional interventions.

Strategies mentioned were:

- Consistency in routines
- One-on-one education programs or home-schooling
- Assistance with transitions in daily routines and life changes
- Reduced stimulation in homes and classrooms
- Avoidance of crowded areas or events
- Direct, consequential reward for completion of task-related commands
- Use of concrete examples in learning situations, along with repetition and reinforcement
- Nutritional alternatives to medications (e.g., limiting sugar)
- Nutritional supplements, such as L-tryptophan
- Visual aids for abstract reasoning tasks (such as time management)
- Allowance of a safe, time-out zone in schools for sensory overload
- Appropriate physical and occupational therapies
- Job coaches for young adults with FASD
- Neurofeedback to increase blood flow to the brain

- Use of hyperbaric oxygen therapy

CONCLUSION

The social implications of FASD were highlighted in the variety of comments at the six Town Hall meetings. Participants openly shared their very intimate struggles in parenting children with FASD, with its heartache, grief, joy, and hope.

Inherent in the testimony was the hope that society will accommodate the special needs of children with FASD and their families. Participants advocated for needed resources for children with FASD so that they can become independent and productive members of society.

Long-term treatment initiatives must include strong prevention initiatives aimed at eliminating FASD by reducing alcohol use during pregnancy. Policymakers and public health professionals need to consider several factors as they work toward these goals. These factors include professional standards for teachers and practitioners, feasibility of public education campaigns aimed at substance-abusing women, and effects of policy implementation on society at large.

The FASD Center for Excellence will continue its collaborative efforts in preventing and treating FASD. Through this continued communication, the field can advance, public awareness can increase, and services can improve. These efforts are crucial, because pregnancy only lasts 9 months but FASD lasts a lifetime.

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- Stratton, K.; Howe, C.; and Battaglia, F., eds, 1996. *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*. Washington, DC: National Academy Press.
- Streissguth, A.P.; Barr, H.M.; Kogan, J.; et al. 1996. *Understanding the Occurrence of Secondary Disabilities in Clients With Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*, Final Report. Seattle: University of Washington Publication Services.
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Appendix A
Town Hall Brochure

Draft

October 18, 2003
12:30 p.m.— 5:00 p.m.

TOWN HALL MEETING

ON

FETAL ALCOHOL SPECTRUM DISORDER

Radisson Hotel City Center
181 W. Broadway, Tucson, AZ

SPONSORED BY
Department of Health & Human Services
Substance Abuse & Mental Health
Services Administration
www.samhsa.gov

FASD Center for Excellence

TOWN HALL MEETING ON FASD

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Draft

Washington PAVE
DASA FAS Project
6316 South 12th St.
Tacoma, WA 98465-1900

This town hall meeting will be a forum for all people who live, love, and work with children and adults who have fetal alcohol spectrum disorder (FASD). The FASD Center for Excellence, established by the federal government through the Substance Abuse and Mental Health Services Administration (SAMHSA), is seeking information about FASD issues and concerns. Everyone impacted by this disability will have the opportunity to talk about personal experiences and to address gaps in services.

These testimonies will be received by a panel comprised of representatives from the FASD Center for Excellence, SAMHSA, Centers for Disease Control (CDC), National Institutes on Alcohol Abuse and Alcoholism (NIAAA) and state/regional public agencies. **Testimony will be summarized and included in a report for Congress, which will outline a national strategy on FASD.**

The mission of the FASD Center for Excellence* is to increase the effectiveness of prevention and treatment options for fetal alcohol spectrum disorder in the United States by providing national leadership and coordination in the field.

Fetal Alcohol Spectrum Disorders Center for Excellence
1700 Research Blvd., Suite 400 • Rockville, MD 20850
www.fascenter.samhsa.gov

*The FASD Center for Excellence was established under section 519D of the Children's Health Act of 2000 and is being administered by the Substance Abuse and Mental Health Services Administration (SAMHSA).

FIRST STEP Town Hall Meetings

As one of the first steps to carry out its mission, the FASD Center for Excellence will conduct a series of regional town hall meetings around the country.

TESTIMONY AT THE TOWN HALL MEETINGS IS REQUESTED FROM:

- Individuals with FASD
- Families of those with FASD
- Professionals who provide services and support to those with FASD

TESTIMONY SUGGESTIONS

- Share your experiences with children or clients who have this disability.
- Keep in mind the main points you want to make.
- Think about issues you may want to address:
 - ▶ Helpful services/interventions you have received
 - ▶ Types of prevention/intervention services needed but not available
 - ▶ Barriers to services
 - ▶ Suggestions for prevention approaches
 - ▶ The most important service or support you need now
- Summarize your testimony in a brief outline so you can give it within the five minute time limit.
- Consider writing down and reading your testimony if you are more comfortable with that. If you do not wish to testify publicly, you may send written testimony to the FAS Family Resource Institute (FAS*FRI), the meeting coordinators.

WANT HELP TO PREPARE TESTIMONY?

A testimony orientation workshop will be held on October 18, from 9 to 11 a.m. Participants will brainstorm about the major points they want to make within the time allowed for testimony and they will be briefed on the town hall procedure.

All events will be held at the Radisson Hotel City Center. See directions below.

TOWN HALL MEETING AGENDA

- OCTOBER 18, 2003 -

- 12:00 p.m. Sign-in sheets available
- 12:30 p.m. Opening statements by representatives from the Substance Abuse and Mental Health Services Administration and the FASD Center for Excellence
- 12:40 p.m. Introduction of Panel Members
- 12:50 p.m. Orientation by FAS*FRI
- 1:00-5:00 p.m. General Testimony

Each person will be given five minutes to testify. All individuals, parents, and professionals impacted by this disability are encouraged to testify. We need everyone! This is a unique opportunity to make your voice heard.

- ▶ If anyone has special needs, please notify FAS*FRI three weeks prior to the event.
- ▶ No childcare will be available.

LUNCHEON RECEPTION FOR PARTICIPANTS

October 18, 2003
11:00 a.m. - Noon

Radisson Hotel City Center
Provided compliments of the
FASD Center for Excellence

ACCOMMODATIONS

Radisson Hotel City Center
181 W. Broadway, Tucson, AZ

Rooms are available at \$58 per night (single or double) until October 1st. Call (520) 624-8711 for reservations. In order to get the contracted rate, please mention you will be participating in the FASD meetings. Parking is complimentary. Free airport shuttle service is provided, based on availability.

SCHOLARSHIPS

A limited number of expense scholarships are available for families. Contact FAS*FRI to apply.

FOR MORE INFORMATION

As a subcontractor to the FASD Center for Excellence, FAS*FRI will coordinate the regional town hall meetings. For more information, or to submit written testimony, contact:

Vicky McKinney
FAS Family Resource Institute
P.O. Box 2525, Lynnwood, WA 98036
(800) 459-4637
E-mail: Vicky@fetalalcoholsyndrome.org

DIRECTIONS TO RADISSON HOTEL CITY CENTER

181 W. Broadway, Tucson, AZ • (520) 624-8711

Take Interstate 10 to Congress/Broadway Exit #258. Head east on Broadway and go approximately 3 blocks to Hotel. The Radisson is in downtown Tucson, adjacent to the Tucson Convention Center complex, within the Historic Arts Districts and across from the federal and state government buildings.

From the airport: Free shuttle service is provided, based on availability.

(conference edition)

Appendix B
Town Hall VIP Panelists

WASHINGTON STATE: MARCH 28, 2002

Annie Acosta, MSW
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MINNESOTA: SEPTEMBER 18, 2003 AFTERNOON SESSION

NATIVE AMERICAN TESTIMONY

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Appendix C
New York Governor's Proclamation on FAS
Town Hall Meeting



Whereas, children are our future and deserve every opportunity to grow up healthy and strong, and enjoy productive lives; and, the use of alcohol and other drugs by pregnant women remains one of the leading preventable causes of birth defects and developmental disabilities that tragically rob children of a fulfilling life; and

Whereas, one of the most severe types of birth defects is caused by alcohol consumption during pregnancy; known as "Fetal Alcohol Spectrum Disorder" (FASD), its effects can be far worse than that of heroin, cocaine, and marijuana - and as the leading identified cause of mental retardation, it is characterized by growth retardation, facial abnormalities, and central nervous system dysfunction; children with FASD also commonly have difficulties with learning, attention, memory, and problem solving, along with coordination, impulsiveness, and impaired speech and hearing; and

Whereas, in order to prevent children from exposure to the dangerous consequences of alcohol and other drugs, it is critical that women who are pregnant or planning a pregnancy be aware of the life altering risks to their unborn fetus; most importantly, they should abstain from alcohol and drug use, as it is harmful not only to their unborn child, but to themselves; and

Whereas, it is estimated that one in ten women in the United States drink alcohol while pregnant and, as a result, nearly 40,000 babies are born each year with FASD; frequent (seven or more drinks per week) and binge drinking (five or more drinks on any one occasion) before and during pregnancy continue to pose the risk of FASD or other alcohol-related disorders; according to research, these categories of drinking quadrupled during 1991 to 1995, and while the overall rate of alcohol use among pregnant women has declined since 1995, current rates of frequent and binge drinking remain at high levels; and

Whereas, New York State is proud to be hosting a statewide Town Hall Meeting on the subject of FASD in the City of Buffalo on May 21, 2003; the goal of this initiative is to gain information and insight from the expressed concerns and views of individuals affected by prenatal use of alcohol, along with family members, educators, service providers and healthcare professionals; it is a unique opportunity for those impacted by FASD to be heard by a panel of National, State and local officials who will listen to those with personal experience, whereupon their testimonies will be sent to the United States Congress to help shape policy on prevention, intervention, and treatment of FASD; and

Whereas, working with researchers, clinicians, parents and teachers, we can help provide a positive learning environment and more rewarding lifestyle for many in the future; as research and knowledge about FASD increases, parents and caregivers of children with FASD will better be able to address the complex characteristics that affect these children and their families;

Now, Therefore, I, George E. Pataki, Governor of the State of New York, do recognize May 11-17, 2003 as

ALCOHOL AND DRUG-RELATED BIRTH DEFECTS AWARENESS WEEK

in the Empire State.



A handwritten signature in black ink, appearing to read "G. E. Pataki".

Governor

Appendix D
Testimony Summaries

Starting the Conversation

Washington State: March 2002		
#	Testifier	Key Points in Testimony
1	Clinical supervisor, program for parents and children	Advocate-mentors helpful; assigning advocates to at-risk women and providing followup care advantageous.
2	Clinical supervisor, program for parents and children	Have received a small grant but still need funding; using FASD advocate approach to intervention and treatment.
3	Advocate, program for parents and children	Works with 15 women and their families; can be difficult; advocates helping put the pieces of people's lives together; 3-year process; transition after graduation difficult.
4	Young adult with FAS	Would like resources to help live independently; need a safe place with supervision.
5	Records analyst and advocate, fetal alcohol and drug unit	Need more effective case management for persons with FASD; recommends lifetime guardian-advocates, even for those who do not have a diagnosis.
6	Advocate in the criminal justice system	Need to make changes in the criminal justice system; no awareness of FASD as a disability; need to screen for FASD among arrestees.
7	Adult with FAS	Diagnosed at 14 with FAS and cerebral palsy; needs help managing independent living, such as personal hygiene and finances.
8	Advocate for services for the disabled	State making money from alcohol sales but no services for persons with FASD; need an alcohol sales tax that would provide services for FASD.
9	Adoptive parent of two boys with FAE	Respite help invaluable; cognitive-behavioral therapy and home schooling helpful; need a holistic approach to FASD with coordinated services.
10	School psychologist	Sees children struggle through school and programs that do not meet their needs; often put in classes for behavioral disturbances; lack of diagnosis causing repeated trips through the system.
11	Adoptive parent	No disclosure of maternal substance abuse by adoption agency; developmental delays first cue; labeled learning disabled; has normal IQ but lacks proper brain functions to use it; need more public education and early diagnosis.
12	Grandmother	Foster care only option without grandmother's help; "isolating life" caring for children with FASD; lack of services, especially respite; need to educate providers; need more funding and help for families.
13	Youth with FAS	Need an "alcohol-free country"; says he feels o.k. but still does dumb things.
14	Adoptive parent of two sons with FAS	Thought love and discipline would change their lives; took 10 years to find out what was wrong; unbelievable stress; at 18, decided to try life on their own; not much parents can do.
15	Youth with FAS	Has problems in school; gets easily distracted by noise and movement; should use alcohol taxes to fund programs for persons with FASD.
16	Mother and son; son has FAS	Son diagnosed at 3; mother told that he would be severely challenged; has trouble with cognitive skills but has many positive attributes.

Starting the Conversation

Washington State: March 2002		
#	Testifier	Key Points in Testimony
17	Youth with FAE	Parents thought he would grow up to be normal; teacher thinks he is normal but he is not; needs help making decisions; "I didn't choose to be a child with FAE."
18	Member of the Tuska Indian Nation	Surveyed 20 tribes; needs centered on increased services and resources about FASD; also need grief counseling.
19	Executive director of a children's academy focused on neurodevelopment and learning	Tells the progress of a young woman with FAE; went from struggling with many developmental delays to overcoming many challenges; wrote a book and won a Tiger Woods scholarship.
20	Adoptive parent	Son escapes at night—tries to run away; drove the family car without a license; do not feel safe at home with this child; need safe place for him; need funding and services.
21	Adoptive and foster parent who works with children	No preparation for caring for children with FAS; took too many years to get services; great strain on family; parents often blamed for children's difficulties.
22	Birth mother of seven children, one with FAS	Son able to get services because of mental retardation; school system forced to serve his needs; hard to stay sober and keep working due to stigma; need organized homes for those with FASD, like Boy's Town.
23	Grandmother raising two grandchildren	Need more consolidation of services, communication between FASD parent groups, new programs that work, respite.
24	Adoptive parent for 30 years; works for the Department of Health	Disseminates information about FASD; provides health care training to professionals; supports children and special needs programs.
25	Foster parent for 13 years	Family takes on children with special needs because they often cannot find a home; difficulty finding school services; need respite.
26	Adoptive parent	Had trouble getting services; cannot find care for 12-year-old with sexual outburst background; told the only way they could get help would be for child to break the law; spent over \$2,500 a month until money ran out.
27	Birth mother of child with FAS	Drank 5 months while pregnant; got a diagnosis but has not helped getting services; funding a barrier; built-in services for adoptive families but not for birth parents.
28	School counselor and adoptive parent of eight children	Unprepared for challenges posed by FASD; need to educate the Department of Health and Human Services about FASD; many medical problems and vocational difficulties; some were moved to a group home.
29	Adoptive parent	Adopted daughter as infant; has had problems in school with rage and abusive threats; has many social skills problems; educational system needs to provide adequate training and services for these children.
30	Adoptive parent	Had to learn how to read the emotional troubles of their daughter; she destroyed the home with knives; need more outreach services in times of crisis.

Starting the Conversation

Washington State: March 2002		
#	Testifier	Key Points in Testimony
31	Researcher who works with a curriculum aimed at helping families with disabled youth	Neurobehavioral and neurodevelopmental strategies helpful, as well as art therapy.
32	Adoptive parent	Volatility biggest problem; emotional ups and downs; education a major issue; hard time finding a psychiatrist who can help; have tried many medications.
33	Sibling of girl with FAS	Sister spat and was abusive as a child; as they got older, tension and resentment grew over differences in abilities and opportunities; need sibling support groups.
34	Worked with children's services for 33 years; adoptive parent	Need the community to understand this disability; education a problem, especially in middle school; early diagnosis essential.
35	Adoptive parent who works in the educational system	Recognizes the need for great changes; most States noncompliant with IEPs; need tailored and effective educational programs for every child.
36	Sibling of boy with FAS	Legally free to do as one pleases after age 18; siblings concerned that they will be unable to provide their brother everything he will need.
37	Adoptive parent	Many behavioral difficulties, often resulting in hospitalization; many medical problems, including a kidney transplant; diagnosed with many problems.
38	Advocate	Need to increase prevention efforts; need to do more for public education; need to understand that persons with FASD are not just born to alcoholics.
39	Adoptive parent and chemical dependency counselor	Accused of being a bad mother because of dietary restrictions; FASD misunderstood; does not fit into any other categories; children have mental retardation and behavior problems.
40	Adoptive parent who works with Native American reservations	Problems with unemployment and a fast-growing wine industry; sweat lodges helpful in calming children with FASD; have buried 15 people in the last 7 years because of drugs and alcohol on the reservations.
41	Stepparent of child with an FASD	Not many services available; no respite care providers; violent outbursts; other siblings learning bad behaviors; will need lifelong supervision.
42	Mental health counselor with a family member with FAS	At least one-third of clients fit profile of prenatal alcohol exposure; uses neurofeedback to train and exercise the brain; uses nutritional supplement L-tryptophan and exposure to hyperbaric oxygen chamber.
43	Adoptive parent	Difficult to get services; educators do not recognize disability because of high IQ; educators do not know how to handle behavior difficulties; need to recognize FASD as much as autism, cerebral palsy, Down syndrome, etc.
44	Director of government office devoted to American Indian issues	Got the governor to declare one month as FAS awareness month; Indians suffering greatly from FASD; 40 percent higher rate than the general population.
45	Staff of a clinic and a government office devoted to American Indian issues	Did a survey of tribal needs; need basic services, advocacy, and case management; FAS not a focus of tribal councils; need greater knowledge and awareness.

Starting the Conversation

Washington State: March 2002		
#	Testifier	Key Points in Testimony
46	Half Native American and Pealt tribal member; siblings born with FAS	Maternal alcohol use during pregnancy; drank to avoid spousal abuse and abuse of children; children placed in foster care; testifier in over 25 foster homes; robbed of childhood by drugs and alcohol and generations of FAS.
47	Grandmother of a child with FAE and a social worker with adolescents	Grandson in jail because he cannot make good decisions; at least 70 percent of young social work clients affected by drugs or alcohol; MRI effective for FASD testing.
48	Grandparent	Grandson in jail; currently depressed and does not want to live; raped in jail and received no counseling or help.
49	Foster parent of a severely disabled child with FAS	Medical problems, mainly with spine malformation; trouble maintaining weight; efforts by court to reunite with birth mother; cannot get services as a foster parent.
50	Care provider for a severely disabled child	Working with this type of child very challenging; have to work on personality issues to manage anger; parents in need of respite more than personal care providers.
51	Foster care program coordinator with the State	Support groups helpful but not available to many mothers; society's acceptance of alcohol a barrier to services; need ways for parents to help their children lead fulfilling lives.
52	Worker with the FAS Interagency Workgroup	Intervention complicated because FASD does not have a home; need more collaboration across Federal agencies; need to look at best practices; need funding.

Starting the Conversation

Colorado: June 2002		
#	Testifier	Key Points in Testimony
1	Person with FAS	Misdiagnosed with ADHD; did not receive help needed in school; not allowed to participate in social activities because of behavior problems; threatened with physical violence by teacher.
2	Adoptive parent of five children prenatally exposed to alcohol	Educators big obstacle; IQ restrictions exempting children from needed services; home schooling helpful.
3	Birth parent of young adult with FAS	Other children to be tested soon; many medical problems; son has been in jail already; needs accessible and consistent treatment.
4	Person with FAS	Just graduated from high school; many problems in school; always felt stupid; wants to be a fashion designer.
5	Parent of a child prenatally exposed to alcohol	Got custody when child was 1; misdiagnosed as failure to thrive for which father felt responsible; social services sometimes more of a hindrance than help; need greater sensitivity to persons with FASD and special needs.
6	Adoptive parent	Found that adoption agency had lied about child's problems; need an education system that can meet needs; need school districts supportive of disabled persons.
7	Adoptive parent of two children with FAS	Problems gaining weight; rigid structure in the home key to parenting success; need community awareness about FASD for more sensitivity.
8	Neonatologist and pediatrician	Need affordable and available substance abuse treatment, more early support services for children with FASD, training of psychologists to deal with FASD, available respite care for families.
9	FASD service provider	Need to educate pregnant women about substance abuse; suggests court-ordered treatment for women; need community education.
10	Parent of two children with FAS and parent advocate	Problems with violence and rage in children; need a strong support system for families, support from professionals who are educated and resourceful, higher priority on services for children.
11	Adoptive parent of two children with FAS	Was told the children were healthy; problems in school and socializing; teachers unwilling to listen to parents; one child denied an IEP and vital testing put off.
12	FASD service provider	Need more services and awareness of FASD in criminal justice system, services throughout lifespan, available interventions for times of crisis, disclosure laws.
13	Adoptive parent	Daughter has problems socially and in school; poor psychological services and misdiagnoses.
14	Parent of children with FAS and parent advocate	Had to journey to get diagnosis; doctors denied any problems; have to be lucky to get a diagnosis.
15	Adoptive and foster parent	Lack of services due to budget cuts; many diagnoses, like "alphabet soup"; parents must be proactive and demand services as well as educating service providers.

Starting the Conversation

Colorado: June 2002		
#	Testifier	Key Points in Testimony
16	Foster parent for 29 years	Son now in prison; did not know about FASD when he was a child and received no help or services; need help with medical and dental services.
17	Foster parent for 29 years	Need lifetime support, continuous reteaching; lack of understanding in school system and juvenile justice; need respite.
18	Adoptive parent of child with FAS	Many learning disabilities and chronic medical problems; child embarrassed by his disabilities, which affects his ability to keep a job.
19	FASD advocate	Lack of services and lack of coordination between services; need funding to help developmental services provide accurate diagnostic resources.
20	Parent of two children with FAS	Need services and understanding about FASD; had to stop trying to control the children and instead understand them; need to have more information in the community and educate the educators.
21	Adoptive parent and guardian	Husband's health affected by stress of dealing with children with FASD; cannot get an accurate diagnosis; social services denies that they have problems related to FASD; need better adoption disclosure laws.
22	Parent of four adopted children and two biologic children	Children have a hard time understanding why other people do not understand their disability; inadequate services; public schools "dangerous" for her children.
23	Adoptive parent	Cannot get adoption subsidy; high-level needs and no way to meet them; need behavioral intervention resources, adequate psychiatric care, funding for therapy.

Starting the Conversation

Texas: June 2002		
#	Testifier	Key Points In Testimony
1	Physician, assistant professor of pediatrics, and neonatal perinatal specialist	Praises support from the March of Dimes; FASD 100 percent preventable; need professionals to get rid of the judgmental attitude.
2	Executive director of an organization that develops programs for disabled youth	Need attitude change among professionals; need to train professionals about FASD.
3	Volunteer who helps increase FASD awareness	Need to target alcohol promotions to children and change them; need to increase awareness at bars and restaurants.
4	Birth mother of a child with prenatal alcohol exposure	Drank and used cocaine; child diagnosed at 3 years; noticed developmental delays; received very poor to no counseling in treatment centers.
5	Parent	Many medical problems; very bad education resources; IEP ignored by the school; told that the rewards of teaching a child with FASD are slim.
6	Child with FAS	Appreciates the help received from Easter Seals; has had a hard time in school so home schooling has helped.
7	Adoptive parent of six children, four with FAS	Schools the biggest challenge besides medical problems; teachers overlook the deficits; CPS should screen for FASD; schools need to be held accountable.
8	Educator who works in school-age alcohol education program	Need to educate young people about underage drinking; need to get FASD curriculum in health books; wants to teach young people the facts, not fear.
9	Adoptive parent	Did not understand the problems of FASD when they adopted; need to bring this disability into the public's vocabulary; FASD "invisible disability"; child doomed to mediocrity without proper help.
10	Stepparent of two children	One son currently incarcerated; will have to register as a sexual predator on release; would have helped to know about FASD when raising children; need more education for professionals and screening in the juvenile system.
11	Young adult with FAS	Received no support from doctors; focuses on accomplishments more than problems; family support crucial.
12	Executive director of a nonprofit for persons with developmental disabilities	Mental retardation services not enough for those with FASD; denied rights because they do not know what they are entitled to; need to increase funding for real employment opportunities for persons with FASD.
13	Adoptive parent and initiator of an organization for children with FASD	Prevention key; need to support foster parents; need to educate on FASD and cultural attitudes about drinking; need funding for teaching and prevention.
14	Retired pediatrics instructor	Need new criteria for diagnosing FASD; new diagnosis would help the credibility issue.
15	Preacher's wife whose adopted child with prenatal alcohol exposure is in jail	Wants help to learn how to love her child; educators ignored his symptoms; misdiagnosed with ADD; needs supportive and supervised job opportunities.
16	Representative from the Birth Defect Monitoring Division	FASD makes it difficult to do public health surveillance and diagnosis is difficult.

Starting the Conversation

Texas: June 2002		
#	Testifier	Key Points In Testimony
17	Young adult with FAS	Homeless at times; abused in group homes; wants to live independently but cannot manage money; great amount of pain and anger about social stigmas; tired of being a guinea pig for therapies and medications.
18	Aunt of child with FAS	Unaware of her niece's horrible living conditions; tried to help but did not understand the scope of FASD; still struggles to get services.
19	Adoptive parent and special education teacher	Safety a big issue; son hospitalized for aggression and incarcerated twice; misdiagnosed and medicated; without help, become a ward of the penal system.
20	Director of female services with a State alcohol and drug agency for over 20 years, working with addicted women	Addiction overwhelms a woman's ability to protect her children; must not be shamed or blamed into treatment; need interagency planning and coordination.
21	Adoptive parent, professional home care provider, and teacher	Child diagnosed as "too high functioning" for services; need support for families; prisons full of persons with FASD who get no help.
22	Physician in charge of women's health for a corrections department	Population that physicians do not want to deal with; many barriers for women to get treatment in prison, mainly obstacles of bureaucracy; need supportive legislation for criminals needing treatment.
23	Physician; interim vice president at university health department; FASD researcher	Alcohol interferes with brain development, causing abnormal pathways; alcohol one of the most severe drugs a developing fetus can be exposed to.
24	OB/GYN nurse	Professionals still saying it is o.k. to drink while pregnant barrier to prevention and treatment; doctors reluctant to advise patients not to drink; need to examine attitudes about alcohol.
25	Anthropologist, Texas Center for Mental Health Studies	Misinformation given to pregnant women; numerous problems with education system; education motto should be "leave no child behind."
26	Mother of four adopted children with FASD	Education hardest thing; could not find special education services; professionals not educated about FASD; parents often blamed for child's disability.
27	Executive director of child services charity in Mississippi	No FASD services in the State; learning from the Internet; many misconceptions about women at risk for having children with FASD, for example, only alcoholic women having babies with FASD.
28	Adoptive parent	Texas weak on information about FASD; need more books and pamphlets about FASD and where to go for help; need help with schools, should not have to sell the school system on FASD.
29	Southwestern Texas Social Work professor; has worked with birth defects since brother had Down syndrome	"Customer satisfaction" should be the beginning of a revolution for services for people with FASD; families should not have to beg for services; need more community sensitivity to the issues surrounding FASD.
30	Assistant Professor of Behavioral Sciences at University of Texas, Austin	Weak on intervention; using a discovery approach to find out what families affected by FASD need.

Starting the Conversation

Florida: July 2002		
#	Testifier	Key Points in Testimony
1, 2	Adoptive parent of twins with FAS testifying with adoptive daughter without FAS	Severe medical problems; have spent \$220,000 with no assistance; need doctor training and awareness; need respite; need health care based on diagnosis.
3	Adoptive parent	Son has had 56 surgeries, which cost over \$5 million; has 18-year-old who functions as a 3- to 4-year-old; problems with medical and school system mishandling; no services because Florida does not understand FASD.
4	Adoptive parent and social worker	Good services until family split up; person with an FASD shuffled around family members; dropped out of school and now needs help with job and money management.
5	Consultant to Florida Department of Health	Need funding for education, more referrals for substance abuse treatment, more prevention.
6	Manager of residential services for women and children	Alcohol almost always the primary addiction; cost of services for a child with FASD around \$2 million; need more funding.
7	Manager of a community living project	Medical professionals need to be more accountable; realize that women in treatment often have FASD; treat pregnant women as a priority.
8	Adoptive parent	Son in jail twice; lawyer had never heard of FAE; need more awareness and early diagnosis.
9, 10	Foster parents	Many medical problems; received no help with diagnosis; misdiagnosed over and over; mental health issues the most severe; need to train counselors about FASD.
11,12	Adoptive parents	Told child has no problems; diagnosed as hyperactive; did not "fit the mold of learning disabilities"; need open adoption records; wonder "what will happen to him."
13, 14	Addictions counselor and birth mother of child with FAS testifying with child with FAS	Drank wine during pregnancy; had to dig for information on FAS; no housing or services available until one parent reaches 55; daughter now wants a job and needs help.
15	Social worker and consultant for Department of Health	Gives presentations on FASD and formed a network; currently drafting an FASD manual; need more funding.
16	Foster parent	Had several children with prenatal drug exposure in and out of her home; wrote a book on her experiences with one young lady with FAS.
17	Manager of a community-based program	People unaware of FASD; need more attention; poor access to prenatal care; need more critical case management.
18	Stepparent	Has to research stepson's disability; read a book on FAS by Michael Dorris that helped to identify symptoms; have learned good things from son with an FASD, like patience.
19	Social worker and foster parent of child with FAS	Thought love would cure FAS; never seen anything in her work like FAS; has never had any respite; pray "to live one day longer" than child so that child will not be alone.

Starting the Conversation

Florida: July 2002		
#	Testifier	Key Points in Testimony
20	Parent in recovery	Noticed developmental delays in child; had many battles with the schools; need more funding for services; need male mentoring programs for youth.
21	Employee of the Centers for Disease Control and Prevention	Need to realize that Florida is ranked fourth in the Nation for birth defects.
22	Aunt who adopted niece with FAS	Had a hard time finding services and special education; child now going to a "free school," which helps; got Internet support; feels "my job shouldn't be an advocate."

Draft

Starting the Conversation

Illinois: August 2002		
#	Testifier	Key Points in Testimony
1, 2, 3	Adoptive parent of twin grandchildren with FAE testifying with twins	Mother died of alcoholism; twin boys do not think of consequences; crave sugar and cigarettes; grandparents worried about their future.
4	Director of the a family support group	Provides information on FASD to families and professionals; also provides education and resources; desperately in need of funding.
5	Personal care worker for disabled persons	Need more workers; need better training of those working with persons with FASD; need better benefits.
6	Adoptive mother of profoundly affected daughter (young adult)	Hard to get services; no one to help with care; need trained health care providers; need money for diapers and daily needs.
7	Researcher at the University of Wisconsin Medical School	Need seminars and education on FASD; need more prevention messages and a model for pregnant women to follow.
8	Birth parent of 12-year-old	Doctors poorly educated about FASD; lost Medicaid due to family income; need schools to be licensed and mandated to serve disabled persons.
9	Aunt raising her sister's children	Has 16-year-old with FAS; birth mother on her way to prison; son put in classes with children with behavioral problems; cannot get adequate resources because she is not the birth mother.
10	Director who works in intervention	Try to keep families together; need funding for transition services.
11	Volunteer for an outreach program	Need to modify schools to accommodate FASD; need to train teachers, increase public awareness.
12, 13	Adoptive parents	Thought they adopted healthy child; misdiagnosed with ADHD; spend most of their time making doctor's appointments.
14	Adoptive parent	Schools not adequate; have three adopted children and all have education problems.
15, 16	Adoptive/foster parents for two children with FAS	Prenatal alcohol exposure never discussed; need a public awareness campaign; early diagnosis key to effective interventions.
17	Former worker with FEN	Middle school resources exceptionally poor; need to educate children with FASD socially; do not have a label for FASD in schools other than behavior problem.
18	Social worker with children and teens	Need more recognition and awareness of FASD; poor allocation of resources for FASD prevention.
19	Aunt who adopted her sister's children	Need to teach doctors about FASD; children have many problems with rage and multiple hospitalizations.
20	Adoptive parent of an international child	Came from Russia with a disability; parents never told about FAS; doctors misinformed about FASD and treatment.
21	Adoptive parent	Took 10 years to realize that the diagnosis of ADHD was wrong; need more nationwide awareness of FASD.
22	Adoptive parent of two children	Behavior problems: bang head, bite, pull hair; have to go to a therapeutic day school; one son hospitalized 13 times in one year.

Starting the Conversation

Illinois: August 2002		
#	Testifier	Key Points in Testimony
23	Foster parent and adoptive parent of four children	Took 13 doctors to rule out Down syndrome and to diagnose FAS; public school not willing to deal with this disability; people afraid to babysit this child.
24	Adoptive parent	Could not get birth mother to admit alcohol abuse so could not get a diagnosis; son has to have special education now.
25	Administrator in a public school	Public schools interested in FASD; need to include FEN and other outreach programs in education process.
26	Adoptive parent	Biggest problem is finding specialists who will accept public aid card.
27, 28	Adoptive parents	Had no early intervention resources; parents faced with providing tutoring and job training skills; need more social skills training for children with FASD.
29, 30	Adoptive parents	Home not safe because their son invites strangers in; hospitalized for drugs and suicide attempts; problems with sexual acting out; need more awareness and more money.

Draft

Starting the Conversation

Michigan: August 2002		
#	Testifier	Key Points in Testimony
1	Parent of four children (including three adopted children)	Misdiagnosed with ADHD; family strain and eventually a divorce; negative impact on other children; family in crisis and needs help.
2, 3	Foster and adoptive parents of two children	Troubles with violence in the home; need better diagnostic tools for discovering FASD.
4	Researcher working on a screening tool for FASD	New developments in alcohol screen; testing fetal fatty acids as a biological marker.
5, 6	Adoptive parent and sibling of child with FAS	Wants more education for professionals and awareness of FASD; suggests incentive sterilization for at-risk women.
7	Person with FAS	Wants to obtain a job but has difficulty; advocates for more prevention efforts.
8	Public health nurse with 7 years in prevention	Need interventions that work; emphasizes the need for local resources; also need funding.
9	Advocate for several Michigan counties	Need to increase awareness of FASD as a disability; need more special education resources in public schools.
10	Person with FAS	Wants a job and employer education of FASD and disabilities; suggests aides for help with school routines and transitioning.
11	Person with FAS	Need funding for medical resources for diagnosis.
12	Adoptive parent of child with FAS	Need better school awareness of FASD; need public awareness, such as signs at alcohol sales outlets.
13	Adoptive parent of child with FAS	Disability not as noticeable after first grade so difficult to get services; need support, help for parents; works in education and cannot get services.
14	Member of Double Arc (Association of Retarded Citizens)	Need to help educators understand FASD.
15	Person with FAS	Wants job and more social outlets or activities.
16	Foster parent	Daughter has poor social discernment; needs a mentor; likes Thunder Spirit Lodge.
17	Director of prevention network	Need media campaign on FASD; need to increase cultural awareness of drinking; need media literacy programs.
18	Foster parent of nine children	Wants better opportunities and diagnosis; found good service only to later lose it; need to educate professionals.
19	Educator and member of the FAS Task Force	Suggests workshops for teachers, judges, tribal leaders, anyone working with persons with FASD; need more awareness of FASD as a disability.
20	Foster parent and retired early childhood educator with experience in FASD	Need better special education awareness of FASD, better advocates, knowledge of the spectrum of effects associated with FASD.
21	Foster parent for 10 years	Need to recognize FASD as a disability; need more training of professionals who encounter FASD.
22	Person with FAS	School very hard; playing sports very hard; need help for children with FASD to learn how to socialize.

Starting the Conversation

Michigan: August 2002		
#	Testifier	Key Points in Testimony
23	Parent of child with FAS	Had trouble getting a diagnosis; could not get disability or Social Security aid; need education and awareness of FASD.
24, 25	Person with FAS and her mother	Need education and supporters; need a safety zone and telephone numbers for help; need wraparound resources.
26	Volunteer who helps people with FASD	Need better policies and funding for respite care.
27	Parent	Need better diagnostic services and more services in general.
28	Adoptive parent of child with FAE	Better diagnostic criteria; more education for service providers; need recognition of FASD as a disability.
29	Michigan Foster and Adoptive Parents Association (MFAPA) member	Need certified diagnostic centers, classroom aides, more mental health services, more support services.
30	Parent of two adopted children and county FASD program coordinator	Need diagnostic center, funding for services, national campaign.
31	MFAPA member representing eight counties in Michigan	Need prevention and education services, awareness of the spectrum of FASD effects.
32	Person with FAE	Need lifetime advocates, jobs and training for persons with FASD.
33	Parent	Need early services and diagnosis, respite care.
34	Adoptive parent of seven children	Need more mental health facilities and postadoption services.
35, 36	Person with FAS and support person	Need consultation services and education about FASD for professionals, funding for services, access to mental health counseling.
37	Representative with Minnesota Arc	Need training, advocacy, consistent diagnostic criteria, transition services, support groups.
38	Representative with Minnesota Arc	Mission to provide visibility to population, diagnosis, followup, advocacy, research; need consistent diagnostic procedure nationally; need to assess family for needed services; transition to adulthood, employment concerns.
39	Adoptive parent of six children	Has problems with violence in the home; need a long-term residential facility for times of crisis.
40	Judge in probate, juvenile, and family courts	Need more prenatal education for at-risk women; need to realize that prisons are full of people with FASD.
41	Physician in general practice	Need more prenatal education, prevention, intervention; advocacy; need to screen institutionalized people.
42	Parent of three children with FASD	Huge amount of stress on marriage; never enough services to meet needs; need to address high cost of FASD.
43	Adoptive parent of two children with FASD	Need preventive ads, education of professionals about FASD, support groups for parents, options for long-term care.

Starting the Conversation

Michigan: August 2002		
#	Testifier	Key Points in Testimony
44	Adoptive parent	Son diagnosed at age 30; in prison for the third time; need group homes for people with FASD and supervision.
45	Adoptive parent	Was told prison is the cheapest behavioral solution; need jobs for people with FASD and supervision.
46	Adoption services director and uncle of two children with FAS	Lots of frustration for the family; need comprehensive screening, respite, and long intensive family weekends; need to teach parenting strategies for children with FASD; need option of out-of-home placements.
47	Birth mother of a child with FAS	Child misdiagnosed; mother told she could drink during her pregnancy; need prevention at the grassroots level.
48	Adoptive parent	Need very early diagnosis; need a way to keep these children safe; need to get the word out that there is no safe amount to drink during pregnancy.
49	Adoptive parent of child with FAS	Home schools; need support groups for parents and children; faith has helped sustain during rough times.
50	Adoptive parent	History of child being poorly medicated; misdiagnosed several times; need to educate medical field about FASD.
51	Aunt and caregiver to two nephews with FAE	Need help in the home; none available; need vocational training; cannot receive needed SSI benefits.
52, 53	Adoptive parents, one a nurse	Poor services; children abused previously; one child in jail; teachers not helpful at all.
54	Representative for National Disability Rights	FASD still not recognized by Social Security; should not use IQ for measurement; persons with FASD often deprived of their rights and due process.
55	Adoptive parent	Need to raise awareness; need to recognize the high rate of suicide and homelessness in persons with FASD.
56	Adoptive parent	Have tried for over 14 years to get son, 17, diagnosed; son in jail; no services provided when he was growing up; need evaluation for FAS.
57	Adoptive parent of an adult	No services available; poor grades for not turning in work; cannot hold a full time job; needs support, reminders to get medicine, make doctor appointments; concern about care when parents are no longer available.
58	Adoptive parent of an adult with FAS	Suspected FAS and had son examined; school supportive but not much FAS information available; special school, small classes, individualized college program helpful; need residential placement.
59	Researcher	Need more funding, parent-teacher training, communication between parents and professionals, tax-supported shelter.

Starting the Conversation

Alaska: November 2002		
#	Testifier	Key Points in Testimony
1	Special education teacher	Need to promote acceptance of FAS; need more training in the corrections system and resources such as corrections-based diagnostic team; need to examine results of interventions such as FAS-only facilities.
2	Grandparent of a child with FAE and ADHD	Needs constant supervision; unrealistic expectations by schools; suggests respite from university students studying special education; need treatment for birth mothers who have FASD themselves.
3	FAS coordinator at a developmental disabilities agency	Need to recognize FASD as a diagnostic category and as prevailing mental health diagnosis; need more prevalence data, training of service providers, education in schools.
4	Foster and adoptive parent	Hard for foster parents to get services; need to include FASD in developmental disability eligibility categories; need better residential treatment facilities for FASD.
5	Adoptive parent of two children with FASD	Need assisted living and job support for people with FASD.
6	Young adult with FAS	Got teased at school; working 1 day a week and needs support to work more hours.
7	Adoptive parent of four children with FASD and parent navigator with a fetal alcohol resource project	Need to include parents in policymaking; need a more individualized approach to education and service provision—"one size doesn't fit all."
8	Parent navigator for a diagnostic team	Has supported her teenager with FAE to keep him in a mainstream classroom; concerned about children whose parents cannot provide support; need a category for FASD in the medical and educational systems.
9	Parent navigator for a health corporation	Need residential treatment in Alaska; many youth sent out of State; needs to be culturally appropriate; should not treat people with FASD as mental patients; need respite; concern about students with FASD passing benchmark tests for high school diploma.
10	Adoptive parent of children with FASD	Problems with the school system; took children out of school; now in a charter school program; need more education of mental health providers about developmental disability and lifelong nature of FASD.
11	Adoptive parent of three children with FAS and member of regional school board	Need diagnostic teams to visit villages so that the schools can provide appropriate services; had to have her children diagnosed as mentally retarded to get services.
12	Foster parent for 20 years and adoptive parent of a young adult with prenatal alcohol exposure	Son with numerous secondary disabilities; has attempted suicide twice; lack of services and understanding in service systems; difficulty with guardianship once child turns 18; need to educate professionals about FASD.
13	Parent navigator and foster and adoptive parent of two children with FASD	Need education system, mental health, and physicians to take FASD into consideration; difficulty getting appropriate diagnosis; had to quit work and go to the school everyday to help with her child.

Starting the Conversation

Alaska: November 2002		
#	Testifier	Key Points in Testimony
14	Chair of the State Juvenile Justice Advisory Committee, mental services director for a tribal council, past national chair of the Coalition for Juvenile Justice, and past employee of the Division of Juvenile Justice	Conclusion of the Advisory Committee that the best placement is often not the juvenile justice system; read into the record the resolution that the committee passed in support of treatment programs and treatment facilities, including group homes for persons with FASD.
15	Parent of an adult with FAS	Took whole family and community working together for daughter to succeed, such as driving, working, paying bills; found an organization that supported employment and started very young; takes foresight and hard work.
16	Retired school psychologist working on a diagnostic team	Lack of recognition of FASD; not listed in the mental health diagnostic manual, developmental disability categories, or Department of Special Education categories; need training of parents, guardians, schools, daycare providers, and health and mental health providers; need early intervention and prevention.
17	Registered nurse, member of an FAS diagnostic team, member of the local community resource team, and family member of a young adult with FAS	Need supervised housing, case management, education of service providers at the local level, such as vocational rehabilitation, housing agencies, police, and potential employers.
18	Adoptive parent of a child with FAE	Lack of State services; stressful when child sent out of State; need lockdown facilities when open environment unsafe; need to train teachers and physicians; difficult to get diagnosis due to fear of labeling.
19	Superior court judge and member of Alaska FAS Steering Committee	Supports efforts of Division of Juvenile Justice to train staff on FASD and consult with outside experts; need alternatives to jails for people who need structure but do not belong in jail; need diagnosis to facilitate placement.
20	Director of an alcohol and drug abuse program and member of Alaska FAS Steering Committee	Need FASD in the mental health diagnostic manual to facilitate appropriate service delivery; concern about labeling creating a stigma; community diagnostic teams looking for sustainability; team has raised awareness.
21	Birth and adoptive parent of children with FASD, foster parent trainer, and member of FASD Center Steering Committee	Need team approach to diagnosis and treatment; need to help birth mothers deal with guilt and stigma; need to change attitudes such as emancipation at 18 so that parents can protect youth; environmental modification better than behavior modification.
22	Health Canada employee	First Nations health branch against working with brewers on prevention efforts; some individual provinces have had media and other campaigns.
23	Manager for a regional office of the Division of Family and Youth Services	Diagnosis an issue; questioned benefit of FASD being a psychiatric diagnosis; need more training of social workers; need in-State programs to avoid out-of-State placements.

Starting the Conversation

Alaska: November 2002		
#	Testifier	Key Points in Testimony
24	Manager of FAS surveillance project	Undercounting of children with FASD because providers do not know reporting requirements; 14 children with FAS born per year in Alaska and 126 potentially alcohol affected; can collect case data up to age 6 but difficult to obtain records from schools.

Draft

Starting the Conversation

Mississippi: February 2003		
#	Testifier	Key Points in Testimony
1	Social service worker	Part 1 of 3 of the story of Billy, a 14-year-old whose mother was suspected of drinking while pregnant and is now in jail; witnessed domestic violence; problems since age 5; diagnosed with ADHD; held back in kindergarten; lags behind classmates due to social promotion.
2	Social service worker	Part 2 of 3: Brought to social services by his grandparents, who could not control his behavior; legal problems, such as arson, assault; "great kid and very charming" but manipulative.
3	Attorney General's Office employee	Part 3 of 3: Met attorney general in detention; knew that facility was not appropriate; needed treatment, which is hard to arrange, even for attorney general; need funded programs for children with mental disabilities.
4	Aunt	Need professionals to accept different cultures and backgrounds and be open to others' lifestyles, such as the role of spirituality in their lives; need sensitivity training and accountability.
5	Woman in alcohol and drug recovery and mother of four	Lost custody but got children back; not told about FASD or would have stopped drinking while pregnant; need educators to learn about FASD and medical professionals to screen women for alcohol and drug use.
6	Adoptive parent of a child with multiple diagnoses, including FAS	Moonshiner cousins, several with symptoms of FAS; signs of second- and third-generation FASD; need training of professionals and sensitivity to parents.
7	Grandparent	Two grandchildren in detention; older boy disruptive; spends more time at home than in school; need help beyond detention, where they "watch TV all day"; medical information about her daughter's pregnancy unavailable due to confidentiality; daughter never brought home information about alcohol and pregnancy.
8	Clinician serving clients with behavior disorders	Serves 6,000 clients a year, many who may have FASD. Misdiagnosis a problem; need more research on diagnosis and more effective treatment.
9	Adoptive parent of four children with FASD	Early diagnosis and intervention effective; lack of professionals who understand FASD; few doctors taking Medicaid and few therapists experienced with FASD; need respite for families, information for educators, help accessing services.
10	Member of Catholic charity with two facilities for women and children	Sees many children she thinks have FASD; safe, supportive environment conducive to talking about drinking and drug use during pregnancy; need more diagnostic facilities, services.
11	Judge	Lack of resources for youth services; high staff turnover; need incentives for staff to stay, more treatment facilities for women, fewer barriers to service; need to break cycle of addiction by educating children at a young age.
12	Employee of mental health agency	Several programs funded to treat mental health issues; 60 percent of programs provide information on FASD; agency provides limited information on FASD.

Starting the Conversation

Mississippi: February 2003		
#	Testifier	Key Points in Testimony
13	Employee of an agency that provides adoption support and protection services	Serves parents of children with special needs; resources tight; not enough services for parents; need respite, more education of educators and therapists about FASD.
14	Grandparent	Took over 3 years to get a diagnosis; child's violence blamed on poor parenting; ineffective medication; need more education of therapists.
15	Program staff	Program part of the Arc of Mississippi; looking at FASD; educating high school students; limited funding available; medical profession hardest to educate—still telling women to drink a glass of wine in the evening.
16	Birth mother of a young adult with FAS	Will see thousands of adults with FASD in the future as children with FASD grow up, living on margins of society; son an outcast with his peers; will never live independently; need supported housing.

Draft

Starting the Conversation

California: March 26, 2003		
#	Testifier	Key Points in Testimony
1	Adoptive parent of teenager with prenatal alcohol exposure	Disorganized, angry, depressed; cannot learn from mistakes; academic problems, physical problems, trouble with the law, substance abuse; needs a therapist who understands FASD, special education, job training, job coach; need disclosure about FASD during adoption.
2	Birth parent of a child with prenatal alcohol exposure	Drank while pregnant and was addicted to heroin; daughter in gifted program but teacher suspects learning disability; wants more programs for her daughter.
3	Birth parent of a child with FAS	Never heard about FAS in treatment; told by one doctor to drink wine once in a while; wishes there were more programs to help her son and to help her deal with him.
4	Adoptive mother of a young adult	Diagnostic center shut down over concern about labeling; psychodynamic issues, misdiagnosis, uninformed teachers; need housing, diagnostic, medical, education, and alcohol and drug education services; working on legislation; need a State task force.
5	Woman in recovery with four children	Lack of information about FAS; finally in a program where she learned about FAS; needs housing after treatment; need more treatment programs for women.
6	Educational psychologist	Social emotional diagnosis critical; doctors focusing on facial features rather than spectrum; lack of understanding by mental health officials; adversarial school systems; territorial professionals unwilling to listen to "outsiders"; need to inform parents, OB-GYNs, and adoption agencies about FASD; need a conference to explore collaboration; need schools to collect data, screen at preschool level; need to train school psychologists to ask about FASD; need screening in jails, parent advocates, transition programs, juvenile justice system to seek reimbursement from school districts.
7	Woman in recovery	Lives with women who have children with FASD; had never heard of FASD; education very important.
8	Drug and alcohol counselor	Need life skills education; knowledge of FASD lacking; need funding to help birth mothers, many of whom have FASD; need programs for women in treatment to give them a future after they leave; need to break the cycle.
9	Birth mother of child with prenatal alcohol exposure	Currently in a treatment center; focused on getting clean; drank through her entire pregnancy; child looks normal but has problems; need education about FASD; needs tools to be a productive parent.
10	Executive director of an Indian center	Pilot screening project in 1990; 25 percent with FAS; currently serve 50 Indian youth, providing in-home training and advocates for parents; need money and an educational campaign; need to blend western and Indian medicine to address cultural issues.

Starting the Conversation

California: March 26, 2003		
#	Testifier	Key Points in Testimony
11	President of a county foster parents organization	Became involved in foster parenting in 1981 when she fostered a teenager whose baby had different facial features; later learned about FAS; need to provide information through health providers, health centers, schools, parent centers, PTA meetings; need educational advocates, early intervention for youth with alcohol problems, training for parents.
12	Woman in recovery	Did not drink during her last pregnancy but used methamphetamine; need to educate young women; drank occasionally during first pregnancy; would not have if she had known about FAS; doctors asked about tobacco and drugs but not alcohol.
13	Young man with prenatal alcohol exposure	Need jobs for people with FASD so that their parents can work; need to train lawyers and others to help people with FASD; has been in many programs and has been abused.
14	Adoptive parent	Behavior modification, restraint ineffective with FASD; need FASD-specific programs, more supervisors, tracking of infants from birth, recognition of FASD as adaptive functioning disorder and mental health diagnosis; need to tax alcohol to fund prevention.
15	Adoptive parent	Adopted child from Ukraine; suspected FAS but doctor said features were ethnic; having problems in school but not bad enough to stay in special education.
16	FASD researcher	Need professional training on FASD, more funding, intervention for mothers on WIC; brief intervention effective in reducing drinking; people with FASD limited functionally despite high IQs in some cases.
17	Adoptive parent	Held several conferences but thinks public agencies should be more involved; support for education in K-8 but not at high school level; need to add alcohol abuse and sexual misconduct into the curriculum.
18	Adoptive parent	Son diagnosed with William's disease and received services; was actually an FASD; daughter drug exposed; started raging at age 3; at age 6 asked mother to kill her; age 8 now and on medication; does o.k. in school but tests too high for services; finally found out she has FAE.
19	Grandparent of four children	Children exposed to crack, alcohol, and other drugs; retirement and savings affected by demands of grandchildren with special needs; children not going to get better; need services, help, and respite.
20	Adoptive parent of child prenatally exposed to alcohol	Child abused in school; slips through cracks because she does not look disabled; need involvement of justice system, foster care, special education; fear of disclosing FASD because no one will take the children.
21	Adoptive parent of two children with FASD	Children exposed to alcohol, drugs, tobacco; not delayed enough to get services; parents unable to work due to children's needs; should focus less on face, more on brain; need social, physical, emotional help and respite; concern about children's future when parents are gone.

Starting the Conversation

California: March 26, 2003		
#	Testifier	Key Points in Testimony
22	Adoptive parent and special education teacher	Adult son hyperactive with 135 IQ; placed in special education in grade 2; could not get needed information from MRI; problems with the law, housing issues, job problems; no funding for mentor; many misdiagnoses until parent learned about FAS; burden on marriage; causes depression in parent and child.
23	Adoptive parent, resource specialist, and education specialist	Child exposed to alcohol, drugs; hard to get diagnosis; problems with medication; needed behavior specialist; disorganized; does not read; has various therapies and services but needs occupational therapy; need adoption assistance for parents, better training of teachers, umbrella programs to share information and services.
24	Stepmother	Mother in a program but continued to drink; custody given to father; health problems blamed on environment and child removed from home but returned; parents more educated about FASD and child has improved; concerned about preschool and IEPs; discouraged by low attendance of educators and professionals at Town Hall meeting.
25	Concerned citizen	Most people with FASD not dying; will live and drink and reproduce; will go to hospitals time and time again, then the criminal justice system time and time again.
26	Department of Corrections employee	Need broad definition of FASD; professionals hesitant to give diagnoses; need to change attitude of only wanting to hear information from colleagues; need education in all fields and in school system.
27	Adoptive parent and teacher	Child diagnosed with ADHD at age 4; got an IEP; has language processing problems; learning problems not recognized by school; got diagnosis of an FASD; taken off medication; new strategies found; needed special school; physically abused due to uneducated teacher.
28	Worker at a group home for boys	Sees lots of children who probably have FASD; no way to get information for diagnosis due to confidentiality laws; wants to start a support group for parents; need more conferences, physician training, mandatory FASD training in schools and group homes.
29	Group home operator for six teenage boys	Had an IEP for one boy; removed from home because he could not learn; was failing five classes but is improving; schools punishing children for behavior they cannot help; need services after age 18.
30	FAS/FAE Legal Issues Resource Center staff member	Courts, judges, lawyers uninformed about FASD; people with FASD unaware of rights; often falsely confess to please police; resource center addressing legal issues and setting up a Web site, hoping to train police officers, lawyers, judges; already training parole officers.

Starting the Conversation

South Dakota: April 24, 2003		
#	Testifier	Key Points in Testimony
1	Adoptive parent of two children with FASD and special education professor	Daughter, 17, sophomore in high school; has received services all her life but no longer has an IEP; looks and acts normal but has cognitive deficits that people miss; concerns about postgraduation plans.
2	Adoptive parent (spouse of no. 1) talking about adult daughter with FAS	Misdiagnosed as mentally ill; accepts deafness but not FAS; creative IEP; needs lots of support; may lose college grants due to poor grades; guardianship by parents needed due to unplanned pregnancy and criminal activity.
3	Federal public defender	Estimates that 10 percent of clients have FASD; many undiagnosed due to lack of available screening, stigma against drinking mothers; abused in judicial system; need information on placement and support.
4	Adoptive parent of teenager with FAS	Problems with lying; traditional discipline ineffective; income too high to qualify for services; need parenting guidance for adoptive parents; need respite.
5	Native American services coordinator at a center for disabilities	Need to share information on prenatal alcohol exposure and effects on community; nearly one-fourth of women at risk of prenatal drinking; mostly social drinking, regular binges; women drinking before they know they are pregnant; will stop when they know but damage still possible; hard to diagnose FASD; insufficient services.
6	Aunt raising nephew	Problems with school; lack of knowledge about FAS; dropped out due to lack of teacher support; forged checks but planned to repay money; concern about what will happen after high school.
7	Foster parent	FASD in 3 of 13 foster children; terminated one child's arrangement due to violence; concern about whether police understand FASD; need job training or a mentor.
8	Parent of a child with FAS	Child taking 15 pills a day; cannot focus or follow; does not do homework; knows he is behind; wants people to know about FASD so no more people will be like him; need to educate women to be free of all drugs 3 months before they plan to get pregnant.
9	Adoptive parent	Son diagnosed in 1990 at age 14; IQ too high for most services; in and out of jail; no support available after release; did well in a 90-day program and was transferred; now in prison and being abused.
10	FAS researcher	Doing universal prevention on the reservation and surrounding areas; working with birth mothers and women of childbearing age; education most important prevention; very little public awareness; need to educate people who screen mothers in clinics.
11	Treatment counselor and parent of children with learning disabilities	Lack of FASD knowledge in school systems; not enough recognition of FASD; college students being prepared to teach but know nothing about FASD; Center for Disabilities FAS Handbook very helpful; need to add FASD information to college textbooks.

Starting the Conversation

South Dakota: April 24, 2003		
#	Testifier	Key Points in Testimony
12	Director, Community Education and Technical Assistance, university medical school center for disabilities	Lack of knowledge in medical profession about preventing alcohol use during pregnancy; hospitals need to screen women for alcohol use; need to provide doctors with appropriate referrals to treatment centers for pregnant women; need to screen all clients for alcohol use and provide referrals and an intervention team.
13	Probation officer	About 85 percent of adult and juvenile population affected by alcohol; no diagnostic or treatment programs in justice system; no training for parents about justice system; need sentencing guidelines on FASD; people with FASD miss court dates and appointments with probation officers; need alternative approaches.
14	Judge	Judges not trained on sentencing youth with FASD; many mothers lack parenting skills and were victimized themselves; hard to get a diagnosis to determine sentencing; need funding for intervention and treatment; need education of teachers and social service providers.
15	Physician	Insufficient information on FASD.
16	Counselor	Four pregnant women in her program, all with drug and alcohol problems and history of abuse; need a prevention program; need more individual attention for mothers and their children; most clients unaware of FAS and have no idea of the harm they have done to their children.
17	Prevention program staff member	Need more education for teachers, doctors, and community; women affected by alcohol differently than men and need early education.
18	Foster and adoptive parent and chemical dependency counselor	Lack of education and support for caregivers; had to return one child because she could not work with him; tried everything, such as time out, and nothing worked; needed a parent mentor to help strategize.
19	Physician and adoptive parent	Very good education system on reservation; ongoing learning process to meet needs; acceptance of disability important in helping maximize potential; need to start teaching about FASD as early as preschool.
20	Adoption specialist	Want to place children with FASD into good homes; need services in small communities; children who look normal not getting diagnosed; wants Child Protective Services to screen; early diagnosis important in providing services and helping adoptive parents; need support groups.
21	Adopted adult with FAS in alcohol recovery	Native Americans avoid talking about alcohol problems out of respect for elders; multiple generations on reservation with FAS; can get better information on the reservation than from rural areas.
22	Birth mother	Need better special education programs on the reservation; children inappropriately punished; function better with tutors; lack of understanding of FASD among teachers; trying to get Supplemental Security Income.

Starting the Conversation

South Dakota: April 24, 2003		
#	Testifier	Key Points in Testimony
23	FAS project specialist involved in intertribal planning	Native Americans vulnerable; need funding, permanent programs, specialists; education for agencies, staff, families; culturally relevant programs; attention to issues of grief, shame, and blame; birth-to-death services; diagnostic services focusing on behavior problems.
24	Foster parent with a child with FAS	Conflict over diagnosis but too hard to travel for further screening; child aggressive, has dangerous behaviors, does not learn; need services and doctors in the community; need education as a foster parent; hard to know what works because it changes from day to day; need education in the schools about FASD.
25	Prosecuting attorney	Eighty percent of cases alcohol related; child advocacy center for sexual abuse good model for an FAS program; need center for training community members on how to work with FAS.
26	Safe Child Find staff member	Many women stop drinking when pregnant; women continuing to drink come from dysfunctional families or have FASD.
27	Native American who runs a home for abused and neglected children	Has taken care of many children with FASD; one girl cared for from infancy; with care, love, and patience, she graduated from high school; problems after 18, such as drinking and huffing; need help, education, prevention.
28	Program coordinator	Started slowly but grew with outreach to DHHS, probation officers, courts; most clients in third trimester; need early intervention; need postprogram support such as housing and education.
29	Concerned Native American who has cared for family members with FASD	Organized an FAS conference; need an annual conference and support activities; education, starting with young children; alcohol and drug screening for parents; and parent mentoring.
30	Adoptive parent of a teenager	Exhausting spiritually; effective to have a psychologist see parent and child together and separately; public health nurse helpful in getting services; need comprehensive knowledge by professionals and compassion.
31	Educator	Educators very experienced with behavior disorders but FASD is different; hard for teachers and professionals to work with FASD due to lack of knowledge; structure and consistency key; vulnerable to negative peer influence in high school; transition to adulthood hardest time.
32	Adoptive parent	Misdiagnosed many times; no problems seen in school test results; private psychologist found learning disability; got IEP for speech processing disability but not FAS; teachers eager for information about FAS.
33	Internist	Unfamiliar with FASD; awareness problem; tries to be proactive; children often not noticed until they have failed in school and their self-esteem is damaged; need to regulate IEP and 504 plan at State level.
34	Program facilitator of an adult care program	Hard for tribes to access State funds; need to identify people with substance abuse earlier; need education about lifestyle changes specific to Native culture; need support services for families and people in prison.

Starting the Conversation

South Dakota: April 24, 2003		
#	Testifier	Key Points in Testimony
35	Director of a Native American substance abuse association	Oversees 80 counselors; need ability to access available funding to provide treatment and education; no funding in daughter's school for education on FASD.
36	Disability worker caring for sister's nephew	Had to send child to a children's home in fourth grade because school could not meet his needs; high school extremely difficult; said son was lazy and FAS was an excuse; need education on FASD; stopped being a foster parent because of the school situation.

Draft

Starting the Conversation

New York: May 21, 2003		
#	Testifier	Key Points in Testimony
1	Dysmorphologist	FASD an issue no one wants to discuss; need to translate animal research to medical, educational, and human service environments; need to look at genetic risk factors for FASD, screening and diagnosis, and referral; need meaningful collaboration.
2	Woman in recovery	Need social workers and teachers to be aware of FAS and not treat it as a parenting problem; 30-day treatment not enough; need to screen for FASD in children of women in early recovery; need safe treatment environment and facilities for women and their children.
3	Grandparent of adult with FAS	Need to stop pushing people with FASD to be independent; need help and structure; need to respect role of spirituality and religious values in the person's life and not promote behaviors, such as dating, that may conflict.
4	Adoptive parent of an adult with FAS	Not told about daughter's FAS; not diagnosed until age 21; supervision, structure, repetition, and guardians important; daughter's residential home resistant to guardianship, pushing her to work in community despite lack of social skills.
5	Adult with FAS	Problems with math; frustrating when people get irritated when asked to repeat instructions; problem living with lower functioning people; being pushed into inappropriate areas; need to keep high-functioning people together.
6	Employee of prenatal care facility	March of Dimes funding research, conducting seminars, recommending women stop drinking from preconception through nursing, advocating for increased funding for surveillance and prevention.
7	Child with FAS	Trouble doing math, understanding teacher, paying attention; fidgety; can do simple tasks (e.g., cleaning the bathroom); parents helpful with social skills, homework, housework, transitions; warns people about FASD.
8, 9	Adoptive parents	Need early intervention and better screening tools, education of social workers, teachers, and other providers, compilation of parenting techniques, support network; services a challenge because of IQ limits.
10	Educational consultant	Creating a support group; need to educate physicians, social workers, psychologists; early intervention important; need resources for families, such as IEPs, ways to help adults with FASD; IQ limits a barrier to services; high IQ a problem because teachers deny disability exists.
11	Addiction specialist	Works with Native American communities to build culturally based healing activities; 22 percent of Native women alcohol dependent; rarely see connection made between prenatal alcohol exposure and negative outcomes such as poverty and suicide; tendency to judge and punish, rather than to help manage FASD.
12	Native American with FAS	System destroying Native ways of life; children leaders of tomorrow; need knowledge from elders; ideas not recognized because culture not scientifically based; need time to gather our people and ourselves.

Starting the Conversation

New York: May 21, 2003		
#	Testifier	Key Points in Testimony
13	Adoptive and foster parent	Have found various interventions helpful, such as medication, peer groups, art and music therapy, counseling, and environmental manipulation; need to educate service providers, remove barriers between systems; need an advocacy model that supports families.
14	Teacher	Had student with signs of FAS but did not know what was wrong until an FAS presentation; lack of funds for prevention; stigma of addiction a problem; need to teach everyone that no alcohol is safe during pregnancy.
15	Employee with Department of Social Services	Funding an issue; need early identification of FASD and women at risk; making progress in screening; need to screen all women on welfare due to risk of substance abuse; need case management for clients with FASD.
16	Social worker	People with FASD dramatically underserved; teachers and providers undereducated; high percentage of high school dropouts and unemployment; need to intervene and diagnose FASD so that people can qualify for services.
17	Grandmother	Difficulty getting FAS diagnosis; early childhood education program helpful but middle school difficult; educators reluctant to hear about FASD; lost SSI due to IQ limits; caregiving after grandparents' death a concern.
18	Director of an FAS surveillance project	Need population-based surveillance system that uses multiple sources, referral networks that support early and accurate diagnosis, and education of health care and service providers.
19	Psychologist	Need training of obstetric and women-related service staff in substance use screening and treatment resources, periodic bulletins on effective screening/intervention strategies, neuropsychological data in the diagnostic process, and continuing education for school personnel.
20	Adoptive parent of a teenager with FAS	Need education about FASD in medical schools, social service, education, and criminal justice systems, and foster and adoption agencies; need caregiver manuals, specialized group homes, and respite.
21	Adoptive parent	Teachers unable to understand nature of FASD; problems in various school settings; unplanned pregnancies, substance abuse, disappearances, lying, and theft; need safe, supervised environments and jobs where people understand FASD; need to educate professionals.

Starting the Conversation

Washington, DC: June 18, 2003		
#	Testifier	Key Points in Testimony
1, 2	Couple with son prenatally exposed to alcohol	No immediate recall memory; cannot apply things he learns from one context to another; difficulties with school system; high IQ but functions at the mentally retarded level for frontal lobe executive functions.
3	Adoptive parent of two sons with FASD	Many disabilities, emotional problems; did not know the boys had FASD; tried very hard not to adopt children with FASD; ongoing struggle with school system and insurance company; need to educate educators.
4	Woman in alcohol treatment and mother of four	Children in foster care or living with grandmother; oldest child cognitively impaired and struggling in school; attributes one baby's death to alcohol exposure; did not know danger; need prevention.
5	Birth mother in recovery	Drank throughout pregnancy; wants to help herself so she that she can help her son; in treatment and recovery; wants to stay clean.
6	Foster parent of an adult with FAS	Did not identify FAS until daughter was 10; saw many social workers, therapists, psychologists; extreme memory problems, lack of social skills; cannot live independently; taking a community living skills class.
7	Woman in treatment with seven children in foster care	Unaware that social drinking could result in miscarriage; five children have ADHD; worried her children are being mistreated; trying to stay clean and get her children back.
8	Birth mother of an adult with FAS	Hard to get a diagnosis; problems in school, especially with social relationships; desire to be accepted led to harmful behavior such as alcohol use and robbery; no programs that could deal with FAS due to lack of training and guidelines; no FAS programs in Maryland.
9	Nurse and aunt of children with FAS	First became aware of FAS through a patient; need to educate health care providers and get them to advise patients not to drink during pregnancy; need programs to help caregivers; need treatment of alcoholic mothers after a child is born with FAS.
10	Adoptive parent of a daughter with FAS	Many children adopted from former Soviet Union but little awareness about FASD; need pre- and postadoption training on FASD; need to include FASD in special education services in public schools; Ohio initiative, Positive Education Program, integrating mental health treatment and education for children.
11	Program director for a maternal and child agency	Alcohol exposure factor in infant mortality; program staff trained to provide accurate information about alcohol and pregnancy to women of childbearing age; need understanding among physicians, nurses, social workers, parents, siblings, neighbors, and friends.
12, 13	Foster parents of twins	Told that the birth mother abused drugs and alcohol while pregnant and had been in and out of 23 treatment programs; one twin with telltale signs of FAS as a toddler; delays more evident in kindergarten; regular first grade class despite need for special education; got special education after diagnosis of bipolar disorder.

Starting the Conversation

Washington, DC: June 18, 2003		
#	Testifier	Key Points in Testimony
14	Adult with FAS	Struggles with daily activities and school; in her second year of college; failed out of first college; has a retention advisor; only failing two classes now; facing suspension but working on it; has learned to cope with FAS.
15	Adoptive parent	Child given clean bill of health despite being quite small and hyperactive; diagnosed with various learning disabilities; found a doctor trained in FAS and got a diagnosis; need to educate health professionals.
16, 17	Adoptive parents of an adult with FAS	No diagnosis until 32; does not handle freedom well; had to move home; can drive, work, and do volunteer work; needs detailed structure and rules; need adult living arrangements, transportation, monetary supervision.
18	Adoptive parent of a child with FAS	Need physician training on FAS; problems with misdiagnoses, wrong medication; need to highlight strengths and balance limitations; brings educational materials on FAS to school system.
19	Elementary school teacher	Had never heard of FAS until her daughter became involved with NOFAS; need to educate teachers and staff; assessment questions in her school system do not ask about prenatal alcohol use.
20	Member of Alcoholics Anonymous	Born premature to a mother who drank; works at a residential center; often sees pregnant women in the detoxification unit; AA sponsor to a father and child, illustrating the vicious cycle of alcoholism in families.
21	Fetal alcohol prevention specialist and parent of an adult with possible FAS	Received a grant 3 years ago that is running out despite great interest in her seminars; need funding for prevention and early intervention; son lives with his grandmother, lacks social skills, and cannot hold a job.
22	Adoptive parent of a teenager	Repeatedly abandoned by birth mother; changed foster homes frequently; IQ of 55, very poor judgment, extreme signs of depression and anxiety, which threaten her safety; barriers to service such as insurance restrictions.
23	Pediatrician and clinical geneticist	Need testing by child development centers; lack of programs in public schools; need treatment for mothers of children with FASD and case management for parent and child; need transition services for adults with FASD.
24	Birth mother of a daughter with FAS	FAS due to intravenous (IV) alcohol drip to stop premature labor; told by doctor no risk to fetus; no FAS diagnosis until daughter read <i>The Out of Sync Child</i> and made the connection; need to test for FAS in individuals exposed to IV drips in utero.
25, 26	Cofounders of the National Organization on Fetal Alcohol Syndrome	Need more funding for prevention, intervention, public awareness initiatives, treatment for women; not enough gender-specific treatment; Southwest Summit on FAS held recently; need to continue outreach and education and establish local support groups for families.

Starting the Conversation

Washington, DC: June 18, 2003		
#	Testifier	Key Points in Testimony
27	Adoptive parent of adult with FAS	Problems getting care; repeated job failures, drug-related arrest, homelessness; now lives with parents; need care providers for adults with FAS and adequate insurance for treatment; need definite diagnostic standard.
28	Pediatric nurse practitioner	Need statewide birth defect surveillance to support efforts to get research funds; FASD education helping but not enough; upset by lack of resources and services for individuals with FASD.
29	Adoptive parent of three children with FASD	Daily struggle to raise his children; works for prison system; sees many inmates who appear to have FASD; need to break intergenerational cycle of alcohol and drug abuse; need FASD training in prison system.
30	Adoptive parent	Knew something was wrong but doctors said baby was healthy; behavior problems, misdiagnoses, and educational problems; hard to find informed health care professionals willing to work with FASD; concerned about health care costs and insurance restrictions.
31	Director at a children's hospital	Speech problems in children with FAS; delayed verbal skills and vocabulary; need therapy.
32	Director of a treatment foster care program and adoptive parent	Reluctant to mention child's FASD issues for fear of labeling; limited understanding of FASD by professionals; need more awareness and better assessment of children exposed to alcohol and drugs in utero.
33	Adoptive parent of a child with alcohol-related neurodevelopmental disorder	Maternal alcohol abuse documented but not noted as cause of developmental delays; diagnosed with ADHD; FAS not a concern to doctors, who treat the symptoms the same; need to understand that FASD is different.
34	Nurse midwife and birth mother of adult with FAE	Instructed to drink alcohol to offset premature labor; daughter fine until age 14; became destructive, developed eating disorders, and dropped out of college; cannot handle money, lies, and steals; refuses help.
35	Adoptive parent	Cannot get FAE diagnosis due to inability to confirm maternal drinking; diagnosed with bipolar disorder, ADHD, mental retardation, and oppositional defiant disorder; can read and spell well but no social skills; need respite care and social skills training.
36	Adoptive parent of young adult with FAE	Years of misdiagnoses, wrong medications; problems with school system; FAE diagnosed due to inability to confirm maternal drinking; cannot keep jobs due to lack of social skills; befriends wrong people.
37	Nurse and adoptive mother of teenager with FAS	Daughter profoundly retarded and disabled; needs around-the-clock care; lives in a long-term care facility; need access to facilities for children with FASD; desperate and willing to move from Maine.
38	Adoptive parent of a daughter with FAS	IQ of 117; no services available; extremely difficult to explain disability when daughter appears to function normally; need summer camps for children with FAS.

Starting the Conversation

Washington, DC: June 18, 2003		
#	Testifier	Key Points in Testimony
39	Adoptive parent of young adult	Occasional drinking during pregnancy by birth mother; needs great deal of structure; expulsion from school, truancy, frequent stays in juvenile detention; cannot get FAS diagnosis due to insurance restrictions.
40	Adoptive parent	Bizarre behavior, physical defects, and problems in school; FAS not identified until age 20; living in an adult home; making progress; need more public awareness of FASD and treatment for individuals with FAS.
41	Adoptive mother of two children with FAS	Services very expensive; little support from hospitals and school systems; need public and professional awareness, State laws to punish women who drink when pregnant, requirement for alcohol companies to fund research.
42	Psychiatrist	Many physicians unaware of FASD and do not ask about alcohol use during pregnancy; need more definite FASD diagnostic measure; need public understanding of full range of effects of alcohol use during pregnancy.
43, 44	Stepfather of adult with FAS and his stepdaughter with FAS	Need early education of women and individuals in addiction treatment about FASD; need to identify limits and strengths of persons with FASD; stepdaughter talked about things she likes and things she has trouble with.
45	Grandmother and legal guardian of two adolescents with probable FAS	Require special tutoring and integration programs; problem in that they look normal; now have IEPs and are progressing rapidly; concerned that new version of IDEA would withdraw aid from many children who need it.

Starting the Conversation

Maryland: September 8, 2003		
#	Testifier	Key Points in Testimony
1	Mother in treatment	Daughter possibly alcohol affected; need screening and treatment for women and children; long waiting lists; residential treatment effective; no mention of FAS in treatment; newborns screened for drugs, not alcohol.
2	Mother in treatment	Addicted to cocaine and alcohol; used drugs during all three pregnancies; son with ADHD and daughter with problems; in treatment four times; children's behaviors seen as cute by others but are a sign of problems.
3	Clinical psychologist at developmental disability clinic	Educates caregivers on strategies such as repetition; inflated expectations in schools; need to educate health care providers and promote early intervention; need to teach obstetricians not to tell patients alcohol is o.k.
4	Licensed practical nurse and mother in recovery	More focused on children since being in recovery; wants her children evaluated for FAS; used alcohol during last four pregnancies; lost child to sudden infant death syndrome.
5	Mother in recovery	Daughter with special education needs; wants her tested for FASD; medical care a problem without insurance; need more treatment centers that accept women and their children.
6	Single adoptive parent of five children with FAS	Did not want children with special needs; learned of prenatal alcohol exposure from medical records; quit her job due to children's school problems; tried numerous behavioral interventions; crisis intervention due to violent behavior; in-home services unreliable; school system lacks knowledge about FAS; system fragmented.
7	Retired elementary school teacher and member of Al-Anon for 20 years	Three generations of alcohol use during pregnancy; grandchildren have ADHD; estranged from her daughter; had ADD and depression; got treatment; wants Al-Anon and Alateen on FAS resource lists.
8	Physician and mother in recovery with a child with FAS	Drank everyday during first trimester; son's FAS diagnosed at 12; gets special education services but teachers not always cooperative; need code for FAS in educational system; need physician education on FAS.
9	Adoptive parent of a teenager	Son 2 to 3 months premature; healthy when adopted but family never knew what to expect; trying to get a diagnosis beyond ADHD and learning disabilities; needs structure, supervision, and small classes.
10	Adoptive parent of child with FAS	Early intervention and services at a developmental disability clinic; service delay due to managed care; child care difficult to find and very expensive; problems at school; IEP process difficult; need to adapt teaching methods to learning style.
11	Adoptive parent of two children with FAS	Trouble following directions, trust and abandonment issues, unpredictable; vandalism on nine occasions; may have to terminate parental rights to get services; problems at every stage of development; concerned about placement when parents are gone.

Starting the Conversation

Maryland: September 8, 2003		
#	Testifier	Key Points in Testimony
12	Foster parent of four children prenatally exposed to alcohol	Children viewed as inferior rather than as having a disease; circle of friends smaller due to children's behavior; oldest child 21 but developmentally 16; cannot hold a job or parent his baby.
13	Physician at developmental disability clinic	Inadequate services; lack of knowledge among mental health providers; need multidisciplinary physician education, continuum of services, disclosure to adoptive parents, identification of children through infant and toddler programs, FAS screening in any case of substance exposure; lack of support for treatment research due to managed care; disconnect between mental health care and developmental disabilities.
14	Corrections employee and adoptive parent of three children with FAS	Wife homeschooling children; no rhyme or reason to what works; need FAS education for school systems, human services, courts, prisons, law enforcement, health care system; many people in prisons with FASD; need alternative sentencing.
15	Young adult with FAS and in recovery from over-the-counter pill addiction	Diagnosed at 13; called lazy by elementary school teachers because test scores never matched effort; found out she learned differently and got help; structure and self-advocacy helpful; need to educate mental health providers; need a way for children with FASD to vent physically; need employers to understand limitations of persons with FASD.
16	Licensed addictions counselor and birth mother of two adults with FAS	Hid her drinking problem; advised to drink to avoid miscarriage; got into treatment when baby was 2; learned of child's FAS and shifted thinking from "bad" to "brain damaged"; other daughter not diagnosed until 22; need alcohol screening among all women.
17	Director of a nonprofit FAS diagnostic clinic and birth mother of two adults with FASD	FAS never mentioned in AA or counseling; lack of early intervention due to lack of diagnosis; problems in school blamed on poor parenting; need to have FASD as part of core curriculum for every discipline; need to study learning theory and neurocognitive theory because children with FASD learn differently; need shared paradigm and shared terminology to address FASD.
18	Cousin of an adult with FAS	Would not have known about FAS if not for her cousin; as waitress, forced to serve pregnant women who ordered alcohol; need more education on FAS for doctors, teachers, and youth.
19	Father of an adult with an FASD	Problem moving for his job; hard to get services for his son due to strict State residency requirements; many diagnoses; struggled with FASD and mental illness; killed in a hit and run after wandering from group home.
20	Mother in recovery	Oldest child in treatment for alcoholism; sexual and physical abuse of her children due to situations related to her substance abuse; dealing with guilt and shame; realizes she was affected by prenatal alcohol exposure.

Starting the Conversation

Maryland: September 8, 2003		
#	Testifier	Key Points in Testimony
21	Mother in recovery	Drank heavily during her pregnancy with her son; feels guilty; speech and behavior problems in son; results of PCP use during another pregnancy not as bad as alcohol.
22	Mother in recovery	History of alcohol and drug use, criminal activity, jail time, sobriety and relapse, alcohol use during pregnancy; social services unaware she was getting high; thinks her daughter has an FASD; sees problems in her older children; feels guilty about her drinking.

Draft

Starting the Conversation

Minnesota: September 18, 2003		
Open Session		
#	Testifier	Key Points in Testimony
1	Adopted Native American adult with an FASD	Found out about her FASD at 12; treated at psychiatric hospitals and residential center; low teacher-student ratio there helped; ran away from group home, joined a gang; hard to find jobs but found two part-time jobs; living in a group home; would like to live on a ranch.
2	Adoptive parent of 10 children with FASD	Saw problems in children and learned about FASD; diagnosis helpful in understanding problems; home schooling children; school system judging by test scores and not considering FASD; need to teach life skills.
3	Adoptive parent	Need diagnosis to get services; need education, personal care attendants, waivers for help from schools and for parents and family, respite, support groups, assisted living, jobs, life skills training, funding; concerned about children's future.
4	Advocate for families of children with mental health disorders and parent of two adults with possible FASD	Developmental disabilities services for son; not meeting his potential; daughter struggling to meet goals and stay in college; need combined funding streams to provide whole range of services based on best practices.
5	Director of an FASD clinic that provides diagnosis and intervention planning	Need consistent diagnostic efforts nationally; accurate, reliable diagnosis as basis for planning; evaluation of socioeconomics of FASD to pay for management and prevention of victimization of individuals.
6	Staff member at Native American center	Multiple hurdles for families; inconsistent services; vary by race, income, county; often need to be in crisis to get services; services terminated when person improves; hard to get respite; need consistent funding.
7	Adoptive mother of four children with FASD	Hard to get services in schools; many children with FASD end up in prison; diagnosis helps in getting services and special education; need to train educators; need point person for service delivery.
8	Staff member of an organization that provides services for children	Need funding for activities, such as corrected textbooks about FASD; jobs and diversionary programs; adoption subsidies; chemical dependency clinics; education of doctors, teachers, and nurses.
9	Staff member of a caregivers organization	Lack of understanding about FASD; reluctant to enter system because they hope child will get well; educating families about FASD; need more funding and community support for families in navigating system.
10	Adult with an FASD and adoptive father of 10 children with FASD	Worked as a Head Start nurse and learned about FASD and parenting strategies; had to go to North Dakota for mental health services; struggled with schools; need to look at services that provide structure and security.
11	Adoptive parent	Need more diagnosis at birth; problem because people are afraid to talk about drinking; need more awareness among public, schools, and legislators.

Starting the Conversation

Minnesota: September 18, 2003		
Open Session		
#	Testifier	Key Points in Testimony
12	Adoptive parent of a child with an FASD	Rejected for school program but had successful summer with Girl Scouts; put in a problem class and isolated due to disruptive behavior; uncooperative teacher in regular class; need mainstreaming and training on FASD.
13	Parent professional working with mothers with chemical dependency	Lost funding for FASD services; need more time to work with women, funds to coordinate services, such as transitional housing, workforce to serve women with FASD, and FASD prevention services.
14	Adoptive parent of a teenager with an FASD	Diagnosis helpful in dealing with brain injury; focused on developing sensory and motor skills; need to fund programming for families, remove cultural barriers, duplicate successful models such as Thunder Spirit.
15	Teenager with FAS (read into the record by previous testifier)	Drug and alcohol use and prostitution by mother; multiple foster homes; adopted at age 2; destructive, manipulative, controlling; problems in math and other abstract subjects; loved to write and draw; attends CAN LEARN and has improved skills and behavior.
16	Teenager with FAS (read into the record—numbers 15 and 16 are siblings)	Not bonding or trusting as an infant; adopted at 11 months; could not sit up or cuddle; eventually crawled, cuddled, and walked; sensory issues; did not read until 10; destructive; now in CAN LEARN and is improving social skills; made Eagle Scout in Boy Scouts.
17	Grandparent of a child with multiple disabilities and one with probable FASD	Difficult to get services; diagnosis difficult due to pediatrician's concern about labeling; older child o.k. at school but melts down at home; labeled a slow learner.
18	Adoptive parent of twins with prenatal alcohol exposure	Need personal care attendants who understand FASD, public awareness, centers for people with FASD, financial support for families, medication monitoring, services regardless of IQ, watchdog agencies to oversee IEP development and compliance, appropriate educational services, and mandatory training on FASD.
19	Stepmother of two teens with FASD	Noticed major differences in development, investigated what was wrong, and got services for stepdaughter; stepson having problems keeping up at school and has depression; stepdaughter in special education classes; problems with peer pressure, stealing, suicidal wishes.
20	Adoptive parent of 11-year-old twins with FASD	Multiple therapies; average IQ a barrier to school services; had to home school; frustrated not knowing what works; need to educate medical students and physicians about FASD; hard to find social activities.

Starting the Conversation

Minnesota: September 18, 2003		
Open Session		
#	Testifier	Key Points in Testimony
21	Executive Director of State organization on FAS	Need services for women beyond substance use, FASD diagnosis to trigger service eligibility, universal screening tool, single place for diagnosis, treatment, and services, centralized system of diagnostic clinics, respite care, case management, State FASD Center for Excellence, partnerships for prevention, adoption of best practices, research-based prevention campaigns, medical school curriculum, certified trainers, culturally and developmentally specific research.
22	Diagnostic clinic staff	Need to educate professionals and parents about FASD; need separate classification under mental health for FASD; need to have realistic expectations of children with FASD; need to help parents obtain services.
23	Advocate and parent of an adult with an FASD	Daughter with IQ of 117 and high functioning but trouble holding a job or managing the house, such as cooking; needs assisted living; homeless; children living with their father, who uses and deals drugs.
24	Physician	FASD not a low-incident disability; doctors not asking the right questions to determine number of cases.
25	Concerned citizen	Need services and financial support for families, alcohol industry to fund programs, programs for adults with FASD, life skills programs, study of multigenerational substance abuse, training on FASD.

Starting the Conversation

Minnesota: September 18, 2003		
Native American Session		
#	Testifier	Key Points in Testimony
1	Family practice physician for the Native American community	Agency screening all female clients for substance abuse; need to educate primary care providers; need long-term funding; lack of resources and coordination; community health centers good place for diagnostic and support services.
2	Indian Health Board staff member	FASD diagnosis time consuming and costly, not always covered by insurance; need collaborative effort and comprehensive care delivery for treating and tracking FASD.
3	Chemical dependency program staff member	Need more training on FASD; finds resistance to treatment; multigenerational alcohol abuse an issue; not enough funding for programs; need structure to start and maintain a care system.
4	Maternal and child health worker	Need FASD information in schools; scarce resources; pregnant alcohol users missing prenatal care; have locked up women to protect fetus and woman; some success intervening with pregnant women.
5	Adoptive mother of seven children and adults with FASD	One child with FAS, failure to thrive, mental retardation; another being observed in an FAS clinic; gets special education, home schooling; continuous supervision; youngest on 24-hour medical care; hard to get county funding.
6	Adoptive parent of 10 children with FASD and program coordinator	Advantages on reservation of clinics, treatment centers, counseling, training for professionals, parents, and teachers, advocacy for parents, case management, women's circle; need long-term funding; need to focus on children's strengths and learning styles.
7	Training coordinator at a resource center	Mentors helpful to persons with FASD; need more support for grandparents raising grandchildren; family breakup and adoptions by non-Native families factor in Native alcohol abuse and FASD; need research on cost savings of group homes for people with FASD.
8	Letter read into record from adoptive parent of two adults	No FASD diagnoses but one birth mother binged twice late in pregnancy; employment problems; no support from any agency; could prevent secondary disabilities with early diagnosis; need to get rid of stigma.
9	Mother and grandmother	Need to educate educators and correctional and judicial system staff; far-reaching effects of FASD not fully appreciated; not getting much help in urban communities; need funding.

Starting the Conversation

Arizona: October 18, 2003		
#	Testifier	Key Points in Testimony
1	Adoptive parent of a child with FAS and mental retardation	Need culturally appropriate services, on-the-job support system, programs at community colleges, support from IEP committee, postsecondary programs; long waiting list for vocational training.
2	Retired electrical engineer in recovery and friend of a young adult with FAS	Need mandatory FASD education; need to hold fathers responsible for support and care and help them earn money; supports sterilization of women who give birth to multiple children with FASD.
3, 4	Young adult with an FASD and her adoptive mother (testified together)	Needs a job; successful in school with extensive support from mother; offered jobs beneath her potential; has organizational skills but needs help with money management and job coaching.
5	Young adult with FAS	Lives with mother and stepfather; trying to get a job working with children; needs help with money management.
6	Special education teacher	Lack of cooperation between service systems; need more adults at school, training on FASD, ongoing intervention group; need to look at functional and adaptive skills; need to teach children and parents their rights and create positive school climate.
7	Adoptive parent	Suspected an FASD but school psychologist and doctor said no; behavior problems at school blamed on poor parenting; now in prison; probation officer indifferent to disabilities; worried about future when parents die.
8	Grandparent	Need FASD education for teachers, child protective services, health care, and other systems; need better services, early intervention, earlier removal of children from dysfunctional homes, services for adults.
9	Adoptive parent of two children with FAS	Bad behavior starting at 13; emotional disruption for family; son struggling with depression; lack of teacher understanding; lack of funding.
10, 11	Military retirees (couple testifying together)	Caring for a grandchild placed by child protective services; 20 months old and not talking; not sure what to do since traditional parenting methods do not work; concern for child after they die; need funding from alcohol industry for FASD.
12	Adoptive parent of child with FAS (read into record)	Society unable to accept FAS; multiple therapies, IEP meetings, behavior sessions, diagnostic procedures, diet restrictions, medications to develop child's skills; home schooling due to school problems; need to recognize FAS as developmental disability.
13	FAS prevention worker	Need systems to keep children with FASD safe; affected by all systems and areas of society; FASD complex issue; funding limited; need trained specialists onsite in State schools and agencies.
14	Adoptive parent of adult with FAS	Numerous behavior and learning problems; no FAS diagnosis until adulthood; in and out of residential treatment and prison; convicted of murder and sentenced to death; sentence overturned due to FAS; need to fund prevention.

Starting the Conversation

Arizona: October 18, 2003		
#	Testifier	Key Points in Testimony
15	Sister of one adopted sibling with FAE and two with FAS	Frustrating but rewarding; has learned patience, love, compassion; need prevention; need to educate teachers, doctors, social workers; need better IEP compliance; concern for future when mother is gone.
16	Teenager with FAS	Need FAS education in high school; no physical problems but trouble with money, time, numbers; frustrating; need more public awareness.
17	Teenager with FAE	School difficult; cannot remember homework; hard to get a job.
18	Young adult with FAS	Problems with math and memory; taking a college class called Learning Life Skills; helps him to be independent; FASD education and awareness crucial.
19	Birth mother of three children with FASD	Need FASD education for young girls, teachers, social services, health care providers, vocational rehabilitation; need adult services after parents are gone; need to teach people with FASD self-advocacy.
20	Adoptive mother of two children with FASD	Hard to get services; told her daughter was too cute to be in special education; bright but lacks life skills; need services for adolescents and adults.
21	Counselor	Need to bring lawsuit against alcohol industry similar to tobacco lawsuits; need to increase penalty for bootlegging; need to coordinate educational services.
22	FAS program specialist	Navajo Nation only tribe with someone dedicated to FAS issues; need statistics; need to certify doctors and train teachers on FASD.
23	Adoptive parent of three young adults with FASD (read into record)	Need ongoing care due to lifelong nature of disability, inability to learn or respond to normal discipline; need mentors, job coaches, medical help, group homes, assisted living; high cost to families and society.
24	Health care professional	Should share Town Hall testimony with alcohol industry.
25	Adoptive parent of two young adults	No indication of problems; birth mothers' records sealed; early diagnosis of behavior problems, ADD; need an accurate diagnosis to get appropriate services; need to educate doctors.
26	Adoptive parent of young adult	Birth mother alcoholic with no prenatal care; neglected child; died when child was 3; no diagnosis so no services; SSI denied; need help with job placement.
27	Adoptive parent of a Navajo adolescent with prenatal alcohol exposure	Receives services based on mental retardation; daily living skills training, behavior intervention plan; seeking vocational and on-the-job training; needs culturally appropriate counseling; need school activities, family support groups.
28	Adoptive parent of child with FAS (letter from United Kingdom read into record)	Diagnosed at age 4 after long battle; not told of maternal prenatal alcohol use at time of adoption; education system biggest problem; overcrowded, understaffed class; good with horses, riding helpful; trying to raise FASD awareness in United Kingdom.

Starting the Conversation

Arizona: October 18, 2003		
#	Testifier	Key Points in Testimony
29	Director of an advisory counsel on disabilities	Many letters from people who could not travel to Town Hall meeting; harder to diagnose FASD over time as facial features fade; teenagers diagnosed as sociopaths, put into juvenile justice system; need developmental disabilities system to recognize FASD.
30	Mother in recovery with an adult daughter with ARND (read into record)	Many birth mothers of children with FASD alcohol affected; guilt about child's disorder; daughter unwitting accomplice in murder case, sentenced to 24 years in prison; ARND not a defense, only FAS; FAS face only difference; need to focus on behaviors.
31	Immediate past president of the Arc of Arizona	Prevention an Arc priority.
32	Young adult with FAS	Works at a plant nursery as part of vocational rehabilitation program; supervisor understanding about FAS; no trouble with the law due to constant supervision by mother, mentor, brother; engaged and wants to live in a group home.
33	Adoptive parent of two Native American children with FASD	Prevention critical; need public awareness of tragic consequences of FAS; oldest child's decisionmaking skills compromised; fatally shot mother and wounded father and brother; cannot explain why.
34	Sister of a youth with FAS (poem read into record)	Embarrassing, frustrating, annoying to have brother with FAS but not his fault; alcohol the problem.
35	Adoptive parent of a child with FAS (read into record)	Son arrested as a terrorist for response to geography test question; hard to find affordable lawyer who understands FASD; juvenile justice system ill-equipped to handle FASD; cheaper in Texas to incarcerate than educate; FAS Community Resource Center helpful.
36	Woman in recovery and master of social work student	Education crucial; few people going into field of alcoholism; need money for students pursuing drug and alcohol counseling; need to educate young girls.
37	Native American health director and community leader	Alcohol use by Native Americans many times higher than national average; not enough funds for treatment; need to require block grants for tribes; need better communication with tribes.
38	Adoptive parent of two children with FASD (read into record)	Stress on marriage; mother taking on most of child rearing; resents husband's free time; respite every other weekend for 3 hours but often gets cancelled; has developed high blood pressure from stress.
39	Cameraman videotaping Town Hall meeting	Learned a lot about FASD; need to go beyond FAS face in determining service eligibility; need services after age 18, disclosure of prenatal alcohol use to adoptive parents, treatment for women; should punish women who refuse to seek treatment or stop drinking.
40	Birth mother of young adult with FAS	Did not learn about FAS until son was 5; son teased as a child and an adult; life very unfulfilled; cannot pass driving test, does not have friends, vulnerable to peer pressure, needs daily supervision; need to show ugly, shocking pictures of FAS to raise awareness.

Appendix E
Recommended Levels of
FASD Training

RECOMMENDED LEVELS OF FASD TRAINING

Town Hall meeting participants had ideas about various types of training that would help advance the field of FASD. Training was suggested to increase public awareness, manage behaviors, and improve interventions by professionals.

Public Awareness

The public awareness level would be carried out by health professionals using television ad campaigns, short basic videos, posters, pamphlets, and other materials. Those interested would become familiar with resources available on FASD prevention and intervention strategies.

Training on Core Disability Issues

Professionals who have lived with individuals medically diagnosed with FASD for 10 or more years would present training at the core behavioral deficit level. The goal is to organize parents or caregivers who could offer presentations about the behavioral deficits accompanying a diagnosis of FASD. Specific recommendations included persons who have children, adolescents, or adult children diagnosed by recognized FASD researchers such as Dr. Sterling Clarren, Dr. Ken Jones, and Dr. Luther Robinson.

Intervention Strategies

The intervention level of training would ideally come from professionals in health care, developmental disability, mental health, juvenile/criminal justice, chemical dependency, child welfare, vocational, rehabilitation, and education agencies who have taken courses at the core behavioral level. These individuals would have insight from those who have lived with persons with FASD. Professionals who have an educational background in FASD will then be able to apply their professional knowledge in any of the noted systems and help families identify and develop interventions that work for FASD.